

Gathering Stones
One Woman's Personal Journey through Cancer
by Martha Nielsen, Grateful Survivor

There's a time to cast away stones and a time to gather stones together.

Ecclesiastes 3:5

Preface

I am a person who names things. Not just children and pets and stuffed animals, but all kinds of both living and inanimate objects. I started early in life when I named my ever-present blanket “My Nice Clean Gicky,” no doubt my attempt to dissuade my mother from taking it away to wash. I once had a bicycle named Eloise, cars I called Honky and Hot Rod Sterling, and plants I referred to as Ruffles and Sprout. It was therefore no surprise to the people who knew me that when I learned I had a very large tumor in my abdomen and a smaller one in my groin, I named them Goliath and The Philistine.

I was a successful and happily married college professor who taught microbiology to medical students and supervised a nationally funded research program when cancer interrupted my life. I was stunned and understandably frightened, but once I had named the bigger tumor Goliath I could envision it as a known entity. I then began to picture myself as David, the small but resourceful lad who slew the biblical giant.

It took nearly a month after Goliath was discovered for the doctors to decide exactly what type of tumor it was. While we were waiting for the answer, one of my graduate students supportively said, “Once they figure out what Goliath is, we will all help you gather the stones.” After that, any time someone asked what he or she could do to help me, I would say, “Give me a rock,” and thus I began “gathering stones.”

Please understand this is not a book about how to conquer cancer. I make no attempt to give medical advice or provide information about miraculous treatments. It is simply a personal account of how one woman made her way through the maze of dealing with cancer and its treatments. I have written these

words with the hope that someone else might benefit from methods I used to help myself cope and lessons I gleaned as I muddled my way through and fought my way back to health.

When my cancer was first diagnosed, numerous friends gave me books full of useful insights and practical tips interspersed with humorous tidbits. I was thankful for all of them, but I have to admit the first thing I did upon receiving a book was find out whether the author had survived his or her disease. As appalling as it sounds to me now, I only wanted to read books written by people whose cancers hadn't killed them. Somehow I felt their strategies held little promise for me if they had lost the battle anyway. In case that same type of logic applies to you, rest assured if I am no longer alive when you read these words, it is not because Goliath got me in the end. As one friend who was also fighting cancer at the time wrote to me, "What a great visualization tool you've adopted in David vs. Goliath. Everyone knows how that one came out."

My Life Before Cancer



With Husband Jay



At work in my Laboratory



With Daughters Robin (L)
and Erin (R)

THE SAGA OF MY JOURNEY

Mumbling the Mantra of the Mortified

I first noticed a lump in my abdomen early in June, 2003. It didn't hurt, and I even found it amusing that I could push on it and move it around without causing any pain. I was curious about it, of course, but didn't really worry until I realized it was getting larger. By the end of June I asked my gynecologist if she could feel anything unusual during my yearly checkup. She said she didn't feel any kind of mass, but did notice my heart sounds were particularly prominent when she listened to my abdomen with her stethoscope. We figured out later this was due to the tumor transmitting my heartbeat toward the surface, but at the time neither of us thought of that as a possibility. Two weeks later I had a routine colonoscopy and asked the gastroenterologist about my "lump." He dismissed my question by saying, "I didn't see anything in the intestine," but by that time I was becoming more and more convinced the lump was both real and abnormal.

The next day I called my internist's office to make an appointment, but he was leaving town for a ten-day vacation. By the time I was able to see him two weeks later, I had decided to get another opinion if he didn't take it seriously. There was no need for that because he could easily feel it and estimated the size to be ten centimeters, roughly four inches. He told me he didn't know what it was, but he must have been very suspicious because he scheduled a computerized tomography (CT) scan of my abdomen for the following day.

The CT scan was performed early in the morning of August 1, which happened to be the day before my stepson's wedding. I left work at noon that day to decorate for the rehearsal dinner and nearly missed my doctor's call. He said that the CT scan showed a "baseball-sized mass" where we had felt the lump plus a second "penny-sized mass" in my groin that were "most suggestive of lymphoma". The first words out of my mouth were, "But that's cancer!"

Although he agreed I might well have cancer, he softened the blow by telling me, "If you must have cancer, lymphoma is one of the better types to have because it is very treatable." He had already set up an

appointment early the next week for a CT-guided needle biopsy to verify the diagnosis and determine what kind of lymphoma it was since there are more than thirty different types.

Because I didn't want to spoil the wedding festivities, I decided not to tell anyone in my family, including my husband, Jay, what the doctor had said until after the wedding was over. However, I felt a desperate need to tell *someone*, so I called a dear friend named Peg Ricketts whom I knew was a lymphoma survivor. Once I had related what the doctor had told me, I said, "Peg, you have to tell me I'm going to be all right and that I can do this."

As always, Peg's response was perfect. "I can't tell you that you'll be all right because only God knows that, but I *can* tell you that you can do this and I will walk the journey with you." As we talked more, I told Peg I was afraid I wouldn't be able to make it through the wedding without crying. Her advice was to hold something small tightly in my hand that would remind me to pray for strength and courage whenever I felt I was losing control. I took her suggestion and chose a small hardened seed my father-in-law had given me a year before. He had called it a "lucky bean", and I figured I needed all the luck I could get right then.

The lucky bean did its job. Whenever I started to become fearful, I would compose myself by concentrating on breathing slowly in and out while thinking, "Breathe in God's good spirit and breathe out the fear." This simple mantra worked amazingly well and allowed me to get through both the rehearsal dinner that night and the wedding the following day without letting anyone know something was seriously wrong with me.

Later, I used variations of this same breathing technique during many other scary times, such as when I had to undergo bone marrow biopsies or hold perfectly still for prolonged periods as I was transported slowly through one of the scanning machines. Each time I imagined breathing in whatever I needed right then (e.g., relaxation, serenity, courage or hope) while breathing out whatever I needed to get rid of (e.g., tension, anxiety, cowardice and despair). I found these mantras to be invaluable, and they still serve me well in stressful situations.

A needle biopsy was performed three days after the wedding, and my internist called the next day with very scary news. He said the preliminary report from the biopsy was “most suggestive of metastatic small cell carcinoma” instead of lymphoma. If that were the case, the cancer would most likely have started in my lungs, so he wanted to schedule a CT scan of my chest as soon as possible. I felt like someone had knocked all the air out of my lungs because I knew metastatic carcinoma was far less treatable and had a much poorer prognosis than lymphoma.

Although I had never been a smoker, it seemed like I coughed more than usual all that day and night, and with each cough I became more convinced I had lung cancer. I had told my doctor I really didn't want to get any more phone calls from him since he always gave me bad news. However, when he called after the CT scan of my lungs, his voice was less solemn and the news he relayed much happier. My lungs didn't show any tumors and, best of all, further special staining of the biopsy material confirmed Goliath was a B-cell lymphoma after all rather than a carcinoma.

As soon as I found out my lungs were clear, my cough disappeared as quickly and mysteriously as it had started. And to show how nonsensical people dealing with cancer can get, my family and I spent that entire weekend celebrating the fact that I *only* had “lymphoma,” the very same word that had terrified me one week before. That weekend I wrote an email to family members and several friends that ended with the words, *“I will lose my hair and may feel awful, but the ‘cure’ rate for this type of lymphoma is 40-50% and the faster tumor cells grow, the harder the chemo is on them. I figure that having a fast growing tumor like Goliath means he will be one of the wimpy kind who will crumble at the first sign of drugs. And now, Jay and I are going out to celebrate the fact that I have a plain old, sorry-excuse-for-a-tumor B cell lymphoma!”*

I count myself fortunate to have been living in Omaha, Nebraska when I developed lymphoma because several of the oncologists at the University of Nebraska Medical Center (UNMC) are world renowned lymphoma experts and researchers. That includes Dr. Julie Vose, the same oncologist who had successfully treated my friend Peg several years before. I quickly made an appointment with Dr. Vose, figuring that if she could “fix” Peg, then she was the one for me.

Several days later, after a flurry of blood tests, a bone marrow biopsy, and a total body Positron Emission Tomography (PET) scan to search for additional tumors, I saw Dr. Vose for the first time. She told me my bone marrow looked clean and the PET scan didn't show any other tumors aside from the two we already knew about. My cancer was therefore classified as Stage II (out of a possible IV), which sounded good to me since Peg had survived Stage IV lymphoma. However, Dr Vose went on to say that because Goliath was so "bulky," she would need to treat me as if I had Stage III or Stage IV disease. She warned me I might eventually need to undergo a stem cell transplant, which is a modified version of bone marrow transplantation.

Now I imagine few patients would understand those words and automatically cringe at them, but they horrified me. I not only had training in microbiology and immunology, but I had spent the past several years volunteering with stem cell transplant patients at UNMC. I knew how difficult the procedure could be for patients, and the thought of having one myself struck terror in my heart. I therefore decided to put the emphasis in my mind on the word "might" at the forefront of her statement.

Clinging to Control within the Chaos

I have always been one to meet challenges head on. Once I know what I have to do, I can channel all my energies into the task at hand, but having to wait without knowing what to expect can be agony for me. I was eager to get started with chemotherapy because I knew once I was actually "doing something" to fight back, it would give me a sense of purpose and a feeling of power. It threw me for a loop, then, when Dr. Vose said they would first need to perform a second biopsy to obtain additional tissue so they could be certain exactly what type of B cell lymphoma we were dealing with. To my mounting distress as I felt Goliath growing bigger every day, the start of chemotherapy was delayed an additional ten days for the performance of a surgical laparoscopic biopsy and the insertion of a port into my chest to be used for delivering the chemo drugs. Adding to the delay, the biopsy was performed the Friday before Labor Day, so the pathologist informed me it would take an extra four days to obtain the results.

My anxiety level skyrocketed at the thought of waiting even longer, and I said to a good friend of mine who is a physician himself, “I know I can do whatever is necessary to get well, but I just *have to know* what that is, and it’s unbearable to me to have to wait for another four days.” He took me gently by the shoulders, looked into my eyes, and said, “No, Martha, you don’t have to know right now because God already knows and He is taking care of it. All you have to do is trust Him with the knowledge.” My friend didn’t even remember making that statement when I reminded him of it later, but I believe it was God-inspired because it was exactly what I needed to hear at that moment. It seems that patience was just the first of many lessons I was going to be taught by cancer.

The second biopsy report confirmed that Goliath was indeed a diffuse large B cell non-Hodgkin’s lymphoma with “unusual architecture,” which helped explain the initial confusion. Dr. Vose’s plan was to treat me with six “cycles” of a chemotherapy regimen known as R-CHOP, the first line “standard of care” defense against diffuse large B cell lymphoma at the time. A chemotherapy cycle consists of the administration of a group of drugs followed by a rest period of about three weeks to allow the patient’s normal cells to recover from the damage. R-CHOP was composed of four different chemotherapy drugs plus an antibody called Rituxan that binds to B cells and targets them for destruction by the body’s own immune system.

On September 4, 2003, a full thirty-four days after I first learned I had cancer, I finally started my



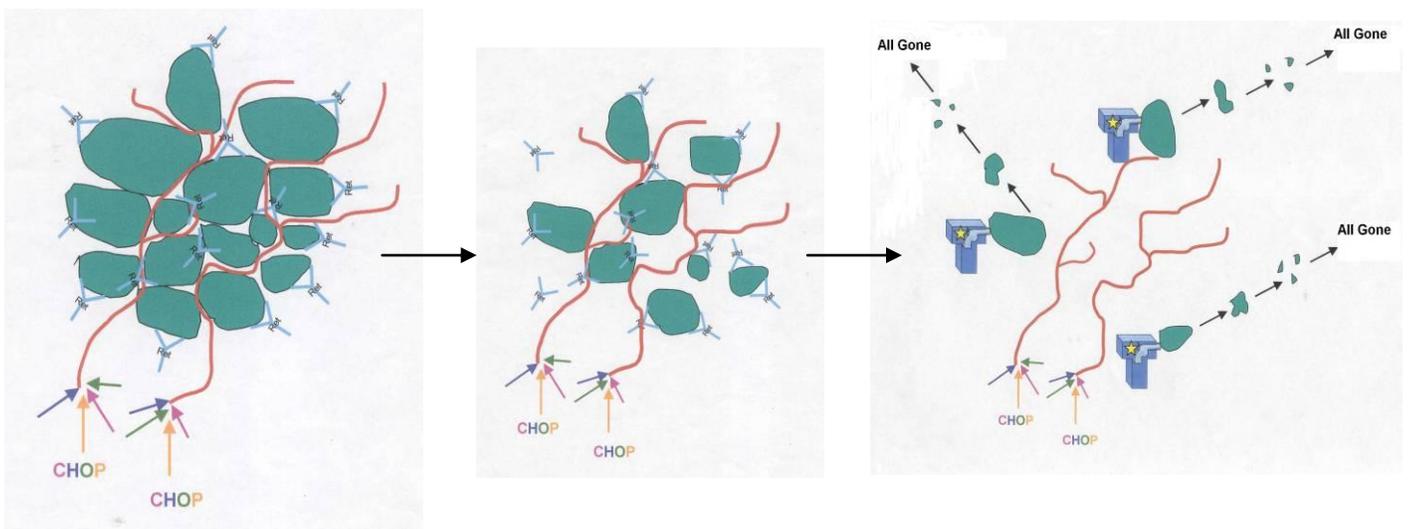
Martha Getting Multiple Drugs Simultaneously

first cycle of R-CHOP. One of my thoughts before my first day of chemotherapy was that five drugs administered at the same time was a huge load for my body to have to metabolize. Imagine my amazement, then, to find out about all the “accessory” drugs they give in conjunction with the chemo to help calm the patient, prevent allergic reactions, and combat side effects like nausea. All in all, I counted that each time I received R-CHOP, I took a total of 15½ tablets of 8 different

medications by mouth plus 5 more injected into my port within a twenty-four hour period. I still find it remarkable that the human body can withstand that type of insult, but at the time I just kept reminding myself Peg had made it through that same regimen. I figured if she could do it, then so could I.

One of the most helpful resources I found early in my cancer experience was a Web site designed by Richard and Annette Bloch (www.blochcancer.org). After reading the Blochs' article entitled "Self Help Exercises," I began to use their relaxation and imaging methods. As instructed, I started by tensing and relaxing my toes and then tightening and relaxing each part of my body in succession as I made my way up to the top of my head. I would then place my hands lightly over the tumor-containing area of my abdomen and imagine my immune cells attacking and killing the tumor cells.

Because of my training in immunology, I knew more than the average person about how the immune system deals with cancer cells. I suspect my imagining was therefore a little more sophisticated than that devised by the majority of cancer patients. I would mentally remind myself that cancer cells are actually abnormal cells that are misshapen and weak and confused, whereas my own immune cells could survive the onslaught of the chemotherapy drugs better because they were "tough"! I used my computer to draw pictures demonstrating wimpy tumor cells being attacked and killed by R-CHOP drugs with the aid of my sheriff-starred, gun-toting T lymphocytes. I will never know if my relaxation and imaging exercises



actually helped cure my cancer, but I do know that when I used them in conjunction with prayer, it helped relieve my anxiety and gave me a sense of empowerment that I otherwise would not have had.

One of the main side effects of most chemotherapy regimens is bone marrow suppression. This occurs because bone marrow cells are some of the fastest growing cells in the body, making them particularly susceptible to the chemotherapy drugs. When a person's bone marrow is suppressed, their blood counts drop. This means they have fewer red blood cells to carry oxygen, neutrophils to fight infections, and platelets to help their blood clot. Each week I was taking chemotherapy, I therefore had to have my blood drawn at the treatment center so Dr. Vose could determine how well my bone marrow was tolerating the drugs and be certain it was safe to give me the next treatment.

During each cycle my counts would drop precipitously ten to fourteen days post-treatment and then start to climb again. This provided me with another activity to help myself feel more in control, as I made graphs charting the numbers of each type of blood cells as they fell and rose again. I cleaned every drawer and closet in our house, putting things in nice orderly arrangements. I also kept track in my journal of my weight, pulse rate, and blood pressure measurements that were monitored each time I went to the treatment center. At the beginning I even recorded the name of each person who took those measurements and each nurse who administered the drugs. Maybe I did all of those things because I have obsessive compulsive tendencies or maybe because I have never been good at remembering names and wanted the nurses to like me. More likely, however, I was just trying to hold on to some kind of power and prove I could still use my cognitive skills. Whatever the reason, these exercises somehow made me feel better and more in control of a situation in which I clearly had no control whatsoever.

As time went on, I got rather used to having low blood counts and it became less scary, but it was a major shock the first time the clinic nurse called me at work to say that my neutrophil count was dangerously low. In fact, it was well below the level I had always described to our medical students as being critical for preventing infections. I did take some comfort in the knowledge that their report also showed I had a lot of "immature neutrophils" in my blood. That is what happens when the bone marrow is pumping out neutrophils very rapidly, kind of like sending out teenaged soldiers when the army runs

out of adults during a war. I wrote an email to my family that night that said in part, *“The nurse told me to be careful and watch for fevers and stay out of crowds, but she didn’t seem overly concerned. I guess they see this all the time, but it’s weird when it happens to you! My infectious disease colleagues say I should stay home today and tomorrow, and by Monday I should be able to go back to work. In the meantime, I keep thinking that if you listen very carefully, you can practically hear my bone marrow pumping out little neutrophils to the rescue as I write this.”*

Toward the end of my first chemotherapy cycle when my counts came back up and I started to feel better, I wrote, *“The happy thought for today is that I should have a whole week now of feeling good before my next chemo treatment. Now that’s something to look forward to!”* However, for all my declarations of good thoughts about the coming week, I found myself anticipating the next round rather than enjoying those moments of relative well-being. Then a friend gave me a bookmark that quoted Psalm 118:24: “This is the day the Lord has made; I will rejoice and be glad in it.” From then on I read that verse each day and tried to remind myself that it makes no sense to ruin a perfectly good day by thinking about what might happen the next day.

I decided cancer patients’ lives are too uncertain to give up any of the good days, and I vowed to make the best of them. Even today I sometimes find myself feeling distressed about the fact that all the chemotherapy and radiation I have been through puts me at high risk of developing cancer again. Whenever I find myself dwelling on such thoughts, I simply repeat, “This is the day the Lord has made; I will rejoice and be glad in it.” After all, I have already had way more tomorrows than any of us expected. What a shame it would be to waste any of them worrying about how many more tomorrows there will be.

Floundering in the Fear of Failure

After the fourth of my six cycles of R-CHOP, I had a CT scan and a PET scan to determine how well the treatment was working. In the best of all possible worlds, neither Goliath nor the Philistine would show any activity on the PET scan, in which case I would simply have received the final two cycles of R-CHOP for good measure and only have to undergo more treatment if the tumors came back. When I went

to the hospital to have the scans, I felt good physically and could no longer feel a lump in my abdomen, so I was hopeful about what they would show. The day of the PET scan I wrote in my journal, *“I am certainly less scared than I was before the first PET scan. I believe there is a good chance Goliath and the Philistine are gone, so I will go with that idea until I find out for sure. If they aren’t gone, I will deal with that then. The thing I need to remember most is that God will continue to watch over me and comfort me no matter what all I have to go through. My job is to be courageous and try to learn whatever lessons I am supposed to be getting from this.”*

I was still holding on to those high hopes when I went to see Dr. Vose to learn the results of the scans. The appointment started out well when she said, “I have good news for you. Your smaller tumor is gone, and the larger one has shrunk to less than fifty percent of its initial size.” Although that wasn’t the news I was hoping for, she explained she hadn’t expected the larger one to be completely gone after only four treatments because it had been so bulky to begin with. Because there was still tumor activity, the plan for my care now became to finish the six cycles of R-CHOP and perform the scans again. If the tumor was completely gone at that time, she would give me two additional R-CHOP treatments for good measure and I would be finished.

I was already unhappy about the idea of having two extra cycles of R-CHOP, but the much bigger blow came when Dr. Vose went on to say I would definitely need to have a stem cell transplant if there was any residual tumor activity at the end of my sixth cycle. That news hit me particularly hard because I had been under the impression I would only need a transplant if I went into remission and then the tumor came back. I had come into treatment with such positivity and high hopes that I couldn’t believe it was really going badly.

I shed a lot of tears that day, which I have always maintained to be therapeutic and cleansing for the soul. My friend Peg had given me a seven-day prayer candle not long after my diagnosis, and I had been keeping one burning constantly in my living room for weeks. When I got home that night, I fleetingly thought about blowing it out. I wrote in my journal, *“I am angry, not so much at God as at the circumstances I find myself in. I feel so helpless and out of control that the ‘constancy of God’ doesn’t*

seem as real as it did before. But the situation IS real and somehow I have to find the strength and the courage to face it and keep up the good fight.”

Just as I believe that crying over bad news is normal and maybe even important, I believe it is more important not to get so caught up in despair that you are unable to go on and do the next thing to help yourself. I therefore went back and reread an article I had found on the Bloch’s website entitled “Ten Commandments to Fight Cancer.” One of their commandments was “Plan for the times you will be depressed.” They went on to explain, “Everything about cancer is depressing including the diagnosis, the treatments and the disease itself. Expect down days and plan things that cheer you up to do at the times you will be depressed.”

I decided that even though it makes sense to spend some time grieving or complaining or being mad, it is critical to then lick your wounds, pick yourself up, dust yourself off, and get back into the ring. The next morning I wrote in my journal, *“As I sit here alone writing, my prayer candle is flickering as if it might go out any minute. At first that seemed scary to me and I felt desperate to keep it lit. But then I realized it is not so much a symbol of God’s flickering presence and comfort, but more a symbol of my own flickering faith and courage. If it goes out, I will simply relight it because I am not going to give up on God any more than He is going to give up on me. He will always be there. It is up to me to stop running away, but instead reach out to Him and the people He sends to help show me the way. God’s light will not go out. I have just temporarily lost sight of it. Dear God, please help me get back on the path so I don’t lose my way entirely.”* In the interest of self-preservation, I literally willed myself not to lose hope as I forged ahead with the fifth and sixth rounds of R-CHOP. Then, just to help myself psychologically, I renamed the big tumor “Golittle” in an attempt to intimidate him while bolstering my own superiority.

Over the course of the next week I wrote in my journal, *“I have gone from abject fear to more of a sense of acceptance of my situation. I used to be so afraid that I would need to have eight rounds of chemo with the possible long-term side-effects that could bring. Isn’t it interesting that now having just eight rounds of chemo sounds really good to me? It really, really scares me to think about having a stem*

cell transplant, even though I know I have the physical and mental toughness it would take. I am still hopeful that won't need to happen, but I am trying not to be too hopeful because I don't want my hopes dashed again. I want to remain as positive as I can because that will make these last weeks of treatment and waiting a lot easier to handle. If I'm wrong and the news is bad, at least this waiting time will have felt better. When I close my eyes to pray and concentrate on killing Golittle, I seem to feel him kind of squirming. It's hard to tell if it's real or imagined, but I will take it as a good sign that he is breathing his last!"

My sixth cycle of R-CHOP came on December 19, 2003, a day I declared as "Kick Butt Day" in my journal. My brother and sister-in-law came to our house for the holidays, and at midnight on New Year's Eve we drank a toast to the demise of Golittle, proclaiming that when I had my scans in January we would be proud to rename him once again – this time to "Gone". However, in the midst of all of our proclamations and collective hopes that the New Year would indeed bring happy tidings, I wrote in my journal, *"I want so badly to believe he will be gone, but it scares me to get my hopes up too high for fear they will be dashed and I will lose sight of hope and courage altogether. However, I know God isn't going to let go of me and let me fall, even if the news confirms my worst fears. I must fight against feeling helpless and small. After all, I am way bigger than Goliath was, even in his prime!"*

Driving by the Doorway to Despair

When I saw Dr. Vose on January 7, 2004, to get the results of my post-6th cycle scans, I knew as soon as she came into the room the news was not good. I had prepared myself for the unhappy possibility I would have to have an additional two cycles of R-CHOP followed by a stem cell transplant, but I most certainly wasn't prepared for an even worse case scenario. She said the tumor had not noticeably decreased in size despite the fifth and sixth R-CHOP treatments, and even a stem cell transplant was unlikely to cure me if we couldn't achieve remission before going into it. This meant I would not have any more R-CHOP treatments, but rather have to undergo at least two more cycles of a completely different "salvage" regimen called RICE that consisted of Rituxan plus three other chemotherapy drugs

not included in R-CHOP. The scans would then be repeated, with the hope that two cycles of RICE would put me into remission. In that case, she would give me two additional cycles of RICE and then start preparations for the transplant. If RICE didn't work, we would have to try yet another regimen.

Needless to say, I was devastated by the news. Once again, I cried – a lot. But once again I also knew I had to keep moving instead of giving up. I envisioned despair as a dark pit with a doorway leading to it. I felt God was holding on to my hand and leading me by the door, and my prayer became a fervent plea for Him not to let go and allow me fall into the pit because I didn't see any way to crawl back out of it if I did.

Dr. Vose felt we needed to give my body an extra week to rest before starting the RICE treatment, so I didn't have the first of those two cycles until January 13, 2004. In my journal I entitled that day "*Fresh Start Day.*" One difference from R-CHOP treatments was that RICE wasn't given in one day, but rather over the course of four consecutive days. On that first day of treatment I wrote in my journal, "*I'm trying very hard today to start with a fresh attitude that we are going to beat this thing. Instead of asking myself why I should be one of the lucky fifty percent or so who are cured of diffuse large B cell lymphoma, I am going to ask why I shouldn't be. Although my chances have decreased considerably now, some people in my situation still do get cured and there is no reason for me not to be one of them!*"

I was anticipating worse side effects from having the new drugs infused over multiple days, but I actually tolerated the RICE treatment even better than I had R-CHOP. In fact, looking back now, I have declared RICE to be my "regimen of choice." The second cycle of RICE went even better, probably because I knew what to expect and didn't stress as much about it ahead of time. Most of the time during my RICE treatment I was able to maintain a strong sense of hope, with very few times of abject fear because I just had a sense the RICE drugs were working. Once the second cycle was over and I had to think about having another set of scans, however, I started to fret again. Each time I received bad news after having scans, it got harder to go into them expecting good news. Since I could no longer feel a lump in my abdomen, there also was no way beforehand for me to get any sense of whether the RICE had

worked as hoped or whether Golittle had also found it to be his “regimen of choice.” I wrote in my journal during that time of waiting for the scans, *“If I wasn’t scared, I wouldn’t be human.”* Then as it came closer to the scan dates I wrote, *“It’s getting harder and harder not to be afraid as the time for my scans gets closer. I know I need to follow Peg’s advice and just ‘walk in faith’, but I am really struggling with fear and a feeling that the tumor is coming back. At first I was so sure RICE was working, but now I have lost that. Every time I have scans they have given me bad news. Shouldn’t it be time for something good to happen?”*

When I went in for the PET scan that time, the technician said he remembered me and was glad to see my name on the list because he liked my smile and good attitude. He said he had a good feeling the results would be better that time. After the scan was finished, I know he tried hard not to show any emotion or give away what he probably had seen on the monitor during the scan, but I could sense that once again I wouldn’t be pleased with the results. I went home and wrote in my journal, *“Although I don’t have any concrete reason for thinking the news will be bad, I can’t seem to get it out of my mind. I am just so afraid the RICE will not have worked and then my chances of something else working will go down even more. I want so badly to believe and be of good cheer, but I also have to be prepared this time for the worst so it won’t hit me as hard as it did last time. The tests are already done, so the die is cast and the rest is up to God.”*

By that afternoon, I became very teary in anticipation of hearing the results from Dr. Vose. Because those waiting periods between the scans and my appointments with her were becoming increasingly difficult as I got more and more bad news, I had started seeing a clinical psychologist. She prescribed a small dose of the drug Xanax, which is normally used to treat anxiety and panic disorders. I found it to be quite helpful in terms of taking the edge off my anxiety during those days of waiting. When I found out that this time I would have to wait over an entire weekend, I wrote, *“I may need to use Xanax for the next few days. I will do whatever it takes to get through this. I want so badly to believe for as long as I can that I will get well. It feels like I have let go of God’s hand, but I know He won’t let go of mine. I just need to hold on more tightly. Instead of thinking that I have four whole days of worrying and not*

knowing, I need to consider that there are four whole days left for me to trust and believe that things are going to be okay.” The following day I felt much better. It may have been because of my own attitude adjustment, but I believe it was mostly God’s answer to my prayers for strength and courage. One way I was able to get through it was by reminding myself I had done everything I could and now I just needed to let go and let God handle it for the next few days.

When the day for my appointment with Dr. Vose finally came, I felt amazingly calm. While sitting in her waiting room I wrote, *“I think I am as prepared as I can be. Of course, I will be really disappointed if I have to do another completely different kind of chemotherapy, but my prayer is that I will be able to accept that with courage and strength if I have to. I firmly believe that God has heard my prayers and those of others on my behalf, but I also know that the answer could be ‘no’ or maybe ‘not now’. My job is to accept the answer I get and then figure out what it is teaching me and what I need to do with it.”*

Looking back now, I find it very interesting that there are no journal entries for over a week after my conversation with Dr. Vose that day. I didn’t write about what she said or about what I was feeling in the aftermath. It’s almost like I didn’t want to remember it, or maybe I was too much in shock and denial to write it down.

Because I have suppressed many of the details of that time period from my recall memory as well, I can only say the news was the RICE treatment had not significantly decreased either Golittle’s size or his PET scan activity level. That meant we were down to Plan C, which was to try two cycles of one more type of even more aggressive “rescue therapy” known as ESHAP that had to be administered as an inpatient. I was to have the treatments three weeks apart, just as before, and then have yet another dreaded set of scans. Of course, the best hope was that ESHAP would put me into remission, giving me a fighting chance of being cured by a stem cell transplant. Even if the tumor didn’t disappear completely, my next best hope was to have it shrink to less than two centimeters because that would qualify me for an experimental clinical trial. In this newer kind of treatment, the stem cell transplant would be performed in conjunction with the administration of a radioactive antibody called Bexxar.

I had read all I could find on Bexxar and learned it is similar to Rituxan in that it binds to the tumor cells, but it contains an attached radioisotope that acts like a guided missile to specifically destroy the tumor cells while sparing most other tissues. Because I was grasping at straws by that time, I somehow convinced myself that Bexxar was going to be my saving grace. I desperately wanted to qualify for the experimental trial because the treatment hadn't been approved yet for patients with my type of lymphoma outside of clinical trials. Getting through the ESHAP treatments and qualifying for the Bexxar trial therefore became my new mission.

Hoping for the Help in Helplessness

I read once in a church newsletter that when we doubt rather than having faith, it makes it very hard for God to comfort us and bring us hope. I don't think that means it's hard for God, but rather that our lack of faith and our constant doubting prevent us from "getting" the messages God sends for the very purpose of giving us the hope we so desperately want.

On March 1, 2004, I started my first cycle of ESHAP, which consisted of one drug I had already taken plus three others I hadn't been given before. I knew ESHAP was a much stronger type of treatment that would also be harder on my body than either R-CHOP or RICE. The day before we checked into the treatment center for the first cycle, I wrote, *"Dear God, right now I am trying ever so hard to be hopeful and brave. I know I could manage whatever bad side-effects the treatment might bring if only I had more hope it was going to work. At the same time, I know all too well that I can't (and even shouldn't) be made privy to that kind of knowledge. All I can do is continue to believe that You are carrying me and You will not leave me to face whatever happens alone. I want to believe that Your answer to my prayers for healing so far has simply been 'not yet' rather than 'no'. Please bolster my flagging courage and get me back to believing rather than wasting my time on the worry and despair that have filled me for the last several days now. It's time to move on. Kick me in the butt if you need to. I have to find a way to get out of the dark place I have fallen into."*

The reason ESHAP therapy requires hospitalization is the drugs are administered as a continuous intravenous infusion over a five-day period. For that inpatient treatment, then, my husband Jay and I checked into a special part of the Lied Transplant Center at UNMC called the Cooperative Care Unit. Cooperative Care is a wonderful innovation in patient care that allows a patient to live in an apartment one floor above the treatment center with a caregiver who must stay with the patient any time he or she is not physically being monitored in the treatment center. There are nurses who administer the chemotherapy drugs plus a “Co-Op nurse” who is available 24/7 for any problems that might arise. However, the patient’s caregiver is taught to do basic tasks such as regularly taking and recording vital signs, recording food and liquid intake and output, and administering and documenting all oral medications.

The rooms in Co-Op are very nice, so much so that I wrote in my journal, *“It would be hard to make the room much nicer or more convenient for the patient and family.”* Jay and I were each given a special credit card with a generous daily allotment for meals and snacks that could be obtained in the hospital cafeteria or their small convenience-type store that was open most of the day and night. We actually felt more like we were staying in a hotel with nursing care than a hospital *per se*. As wonderful as it was, however, we found it challenging for me to be hooked up to an IV pole continuously for five days and nights. That meant there were bags of various fluids that always needed to be changed and tubing that often got tangled and set off an alarm. The first night we were there, the alarm went off at 12:30 p.m. plus 1:15, 2:45, and 3:40 a.m.. Each time we had to call the Co-Op nurse. After that, we got pretty good at figuring out how to circumvent the problems ourselves and even fix things on our own most of the time. I’m sure the nurse must have been as happy as we were about that.

One of the drugs included in ESHAP was an intravenous steroid called methylprednisolone that caused me to retain fluid in a major way. Since they were also giving me fluids continuously, I gained eleven pounds in 2 days, making me feel bloated and uncomfortable. Noting the onset of thick ankles and “chipmunk cheeks” prompted me to write in my journal, *“Oh the joys of taking steroids!”* True to form, though, the doctors were ready and waiting for any and all side-effects. They gave me Lasix (yes, the

same drug they give race horses) to help get rid of the excess fluid. Another effect of the methylprednisolone was to raise my blood sugar to more than twice its normal level, requiring them to give me insulin shots. For me, however, the most distressing side effect of the steroid had to be what I described in my journal as “*weird in the head*”.

One day during my first treatment I wrote in my journal, “*I am having a lot of trouble with weepiness that comes on at the drop of a hat. I seem to have very little control over it.*” Because I was in the hospital over a weekend, I had to see the doctor on call rather than Dr. Vose. He entered my treatment room with an entourage of five or six medical students and residents, and right in the middle of his examination I burst into tears for no apparent reason. I kept trying to explain to them through my sobbing that I was really not that kind of person and didn’t know why I was behaving like that. The doctor simply smiled and nodded. He patted me and told me it was no problem and I was doing much better than some of their patients who go into “roid rages” and try to hit them or pull out their IV lines and announce they are going home. Thank goodness I never got to that point.

When we got back home after my first ESHAP treatment I wrote, “*Each day past the steroids seems to bring me back closer to normal and farther away from the feelings of fear and dread. Next time maybe it will be easier if I recognize the cause and know it will go away with time. The hardest thing for me seems to be finding a reason to hope this treatment will work better than the last two did. If not, Golittle will be officially classified as “chemoresistant.” I try not to look on the internet anymore because the statistics are pretty dismal for someone who has already failed two regimens. Somehow I have to find it inside myself to believe there is still a chance and go on, even when my brain is telling me it’s a lost cause. I know God could choose to cure me at any time, yet somehow it seems more and more like His answer is ‘no.’ I need to find a way to make the ‘bad prognosis’ tapes stop playing over and over again in my head. I know I’m a person, not a statistic, so the ‘odds’ don’t necessarily apply here. It’s just that waiting can be interminable, and this time I can’t seem to find a reason to believe. I need to get some help for this, but I have no idea where to turn for it.*”

My daughter Robin came home a couple of days before I started my second cycle of ESHAP so she could act as my main caregiver in Cooperative Care for that treatment. We had to delay starting the treatment for a few days because my neutrophil count was still too low three weeks after the first one to allow them to give me more chemotherapy. I found that distressing because I didn't want to give the tumor cells any extra time to rest, but once they finally got the first of the drugs started for the 2nd cycle, I wrote in my journal, *"Take that, Golittle! This is going to hurt you a whole lot more than it does me."*

The whole process seemed easier the second time around, partly because I knew what to expect. It also helped that one of the doctors who saw me on rounds several times during the second hospitalization told me he had seen ESHAP work in other patients who had already failed two regimens. Then he said, "We still have a decent chance of curing you." I told him that was the nicest thing anyone had said to me for a very long time.

Even though the doctor's reassurance bolstered my spirits, there were still many times when my hope and courage wavered. At one point while taking steroids in the hospital I wrote, *"I am still struggling with too much fear and not enough hope. The important thing I need to remember is we are doing everything we can. I have remained strong so far and I can keep on going. Maybe Golittle is just extra tough like I am, but if that's so it's just too bad. I am much bigger and more determined and he is weak and confused. One of these days we are finally going to do him in. There's just not enough room in here for both of us!"*

On the last day of that second hospital stay I wrote, *"I'm almost there. It really will be nice to get unhooked from all the tubes and sleep in my own bed, but it's also scary to know this is my last shot at getting into remission or at least getting the size of the tumor down enough to qualify for the Bexxar study. When I get home I will just have to 'walk in faith', as Peg always says. I know I have to be prepared for more bad news, but at the same time I want so badly to believe this third time is the charm and Golittle will become Gotiny or maybe even Gone. These next few weeks will be hard ones, but I have to remember every day I have been given is a gift that needs to be cherished and used wisely."*

Shortly after I got home from the hospital, Peg and I taught a class together for the American Cancer Society's, "Look Good, Feel Better" program. The classes are designed to help women undergoing chemotherapy cope with losing their hair, deal with drying skin and nails, and learn how to use makeup to create the illusion of eyebrows and eyelashes when their own are missing. The class that night proved to be one of the many times when volunteering did at least as much to help me as it did to help the ladies who came to our class. One woman who attended was recovering from a stem cell transplant at the Lied Transplant Center. I couldn't believe it when she told me she had taken eight cycles of R-CHOP and then two cycles of RICE without going into remission, but then ESHAP provided enough of a response to qualify her for the Bexxar clinical trial. That night I went home and wrote, *"Thanks, God – did I ever need to hear about a real person who had failed both R-CHOP and RICE but responded to ESHAP. Now I can remain hopeful and spend less time dwelling on the what-if's."*

Even with all the signs of encouragement I had been given, I found it harder and harder to remain hopeful as the time for my post-ESHAP scans loomed closer. One night I had a melt-down when I thought I could feel a lump pulsating in my abdomen. Then it dawned on me that Goliath never did pulsate himself. I was only able to feel a strong pulse there when he was large enough to conduct my heartbeat to the surface. When I looked at it in this more rational way, I stopped crying and wrote in my journal, *"All of this just shows how distrusting I can be sometimes and how much I need to keep strengthening my faith. The most important thing to remember is that God will always be with me and comfort me regardless of the outcome as long as I don't forget to notice He's there. When my faith flickers, it's not because of a change in God – just a failure on my part to recognize Him. However, a good cry is something we all need now and then."*

The day before I was to go in for the scans I wrote, *"I just need to keep remembering that I have done everything I can to help myself and refuse to ruin today by dwelling on what might happen tomorrow. Heck, I could spend the time instead dwelling on how wonderful it would feel if I find out that Golittle is now Gotiny so I can have Bexxar and thereby a chance for a transplant cure."* By the time I got to the hospital to have the PET scan, I felt more tired than ever before and yet somehow strangely

calmer. The following morning I took a Xanax before my afternoon appointment with Dr. Vose. While in the waiting room I wrote, *“My body must finally be starting to wear down after all it’s been through. I think I am reasonably hopeful, but also prepared for the worst (whatever that is at this point). My job is to trust God that things will come out the way they are meant to. God is in charge. Thank goodness I’m not because I would surely mess it up. Please, God, help me be brave and help me see what I’m supposed to be doing with all of this.”*

Deciding in the Desert of Despondence

When I saw Dr. Vose, she told me Golittle was still essentially the same size he was before taking ESHAP. That meant I not only failed to qualify for the Bexxar trial, but my chances of being cured by the transplant had dropped even lower. Despite all my self-talk about being prepared, I was once again overwhelmed with emotion. Dr. Vose didn’t want to talk about statistics, but I told her I needed to gather all the information I could in order to make an informed decision about whether to even go through with a transplant. At my insistence, she said statistics indicated I only had about a fifteen percent chance the transplant would be successful. Unfortunately, she really didn’t have anything better to offer me at that point. She said she had tried one newer experimental treatment in three earlier patients without success, so neither of us felt that was a viable option. I remember crying and feeling totally devastated, but once again I didn’t write in my journal for a whole week after that appointment. At first I think I was just too sad and maybe even angry (a scary emotion for me) to write anything down. For all of my life, anger had been a very uncomfortable feeling I went to great lengths to avoid. For sure I didn’t think it was acceptable to be angry at God, but the fact remained I was angry at the whole situation. When I finally did start journaling again, my first entry said, *“This wasn’t the way it was supposed to turn out. But this is what we are left with. This is the hand we’ve been dealt. We either have to fold it now and throw it in or make the best possible plays. It is really distressing to me, but such is life (or no life, as the case may be) - BAD THOUGHT!”*

Given our limited options, my family and I decided to go through with the transplant in conjunction with Rituxan treatments in place of Bexxar. The plan was to then follow the transplant with twenty-three days of radiation treatments to my abdomen to help increase the chance of killing the tumor cells. After meetings with Dr. Vose, my case manager, the hospital financial counselor, and a social worker, I began the pre-testing phase of the transplant process. That consisted of another bone marrow biopsy, an electrocardiogram, an echocardiogram, a pulmonary function test, and innumerable blood tests for which they drew sixteen separate tubes of blood! Several days later they called to say I was considered healthy enough to undergo the transplant process. I wrote in my journal that day, *“I am scared – who wouldn’t be – but I know I can get through it. More than anything I am afraid it will all be for nothing, but yet I know that miracles do happen and one still could happen to me!”*

To help my family and friends understand what an autologous (meaning “self”) stem cell transplant was and what it entailed, I explained it was a sort of last-ditch treatment that allowed doctors to give the patient lethal doses of chemotherapy drugs and/or radiation to kill the tumor without killing the patient. One of the main reasons high doses of chemotherapy kill people is damage to immature cells in their bone marrow that have the amazing potential to grow and develop into every type of blood cells the person needs to sustain life. The trick used in a stem cell transplant, then, is to remove some of the patient’s stem cells, store them in a freezer while the patient is given lethal doses of chemotherapy, and then put the stem cells back into the patient.

The first step in the process is to give the patient daily shots of a growth factor that stimulates his/her bone marrow to release stem cells into the bloodstream where they can be collected by a process similar to that used for platelet donation. Blood taken out of the body is shunted through a centrifuge that separates the stem cells from the other cells types so the rest of the blood can be cycled back into the patient. Once a sufficient number of stem cells have been collected and frozen, the chemotherapy is given and then the frozen stem cells are thawed and injected back into the patient’s bloodstream.

As I described it: *“This is when the real fun starts! The day after my last dose of chemotherapy, they will put my stem cells back into my bloodstream. Those little cells are so smart they can find their way*

back into my bones and start making all of the types of blood cells I need to restore my bone marrow function. The problem is this process takes at least ten days to three weeks, which is the hardest and scariest time of all because during that waiting period I won't be able to make any blood cells of my own. They will have to give me red cell and platelet transfusions to keep me alive. During that time I also will be extremely susceptible to infections of all kinds because I won't be making any white blood cells to fight off microorganisms. To make matters even more 'interesting,' I am very likely during that time to have terrible nausea and/or diarrhea and develop painful sores from my mouth clear through my digestive tract. I'm not looking forward to that part, but I have watched plenty of other people do it, and I know I am tough enough to get through it.

I have been told the doctors have drugs to help with each of these unpleasant side effects, and the advice I have had from former transplant patients is 'take the morphine when they offer it to you.' Once I am starting to make a reasonable number of blood cells again (generally two to three weeks), I will be sent home, but I will still have to go back frequently for blood tests and other monitoring for the first couple of months. It will take nearly a year for my immune system to get back close to normal. At that point, they will start revaccinating me for some of the childhood diseases. I look at it as having "baby shots" to teach my new immune system to handle those organisms again. As you can see, this is to be a very long and far-reaching process, but it is also my best hope for recovery. Thanks for 'listening,' and keep those prayers coming. I want God to get really tired of having to hear my name!"

While waiting for the transplant process to actually get underway, I decided to learn all I could about what to expect. I contacted the wonderful people at the National Bone Marrow Transplant Link (www.nbmtlink.org), who put me in touch with three different survivors around the country who had undergone transplants without being in remission. I was especially grateful to a woman named Mary Lou from Connecticut who told me she had been diagnosed with a B cell lymphoma eighteen years before. She said, "I was in stage IV at diagnosis, which is pretty much next to dead." After going through two and a half years of chemotherapy without ever achieving remission, she had what was then considered an experimental bone marrow transplant because it was all they had left to try to save her. Her transplant

had resulted in a complete remission since that time, which gave me the hope I had been praying for so fervently.

I also spent an hour on the phone with a transplant survivor named Ellen, who was incredibly honest and helpful. She said the process was very difficult and she wished I didn't have to go through it, but she would definitely do it again if she had to. I held on tightly to that last part of her statement and remembered it whenever I felt most afraid.

A few days later I was having my blood drawn at the treatment center and happened to be placed in a two-person room with a very nice man named Russ who was recovering from his *second* stem cell transplant. His first one had been performed using his own cells like I would be doing, and the second one was done with cells from his sister. He was very upbeat and comforting, and said it was something he never would have chosen to do, but it was “doable,” a word I now use myself when talking to other people facing transplants. Russ even gave me his phone number and said I could call him any time I was scared and felt like I needed to talk to someone. That day I wrote in my journal, “*Thanks, God, I really needed that!*” The advice and support of all these people meant so much to me that I vowed if I survived I would become a Peer Support Contact for others through the National Bone Marrow Transplant Link. That is a promise I have kept to this day, often offering to other people some of the very advice I found the most helpful.

Preparing for the Possibility of Prevailing

Since Jay had already taken so much family leave time over the previous nine months, we were both relieved when my younger daughter Erin offered to take a three-month leave of absence from her doctoral program to act as my primary caregiver in Cooperative Care at the hospital. She would then stay with us over the rest of the summer while I continued my recovery at home. As grateful as I was to Erin, I felt guilty about wanting her to come. As she herself so eloquently explained it later in a piece she wrote for the National Bone Marrow Transplant LINK, “As grateful as my mom was that I could be her caregiver, it was not an easy thing for her – or for any parent – to accept. Parents want to do the caregiving, and

they want to make things easier and better for their children. My mother felt guilty about ‘uprooting’ my life. It took some time for her to be able to accept that, emotionally, I needed to be there just as much as she needed me there. And let’s face it: as soon as the diagnosis of ‘Cancer’ is made, everyone’s life gets ‘uprooted’ as plans change and priorities dramatically shift.”

Aside from the mental preparation for the transplant, Jay and Erin and I had to attend classes to learn how to take care of me in Co-Op during the actual procedure and then afterward at home. We were taught about precautions to avoid infections and what I termed in an email to the rest of my family, “*other lovely-sounding side-effects that might happen*”.

We also learned how to take care of the external tubing of a second catheter that would be inserted through my chest wall and tunneled into one of the main blood vessels of my heart. As I was waiting in the pre-op area for that catheter to be placed, I wrote, “*I am anxious about having it put in, not so much the procedure itself, but more the idea of having tubes sticking out of my chest. Most of all, I think it is a symbol that the transplant is really happening. I don’t think I’ve exactly been in denial, but it was more abstract before and more real now. The other hard thing is thinking about the fact that going through all of this is still unlikely to get rid of Goliath. I do believe that a miracle could happen – after all, somebody has to be in that fifteen percent. I mostly need to hang on to the fact that God will still hold my hand and walk with me no matter what the outcome or what I have to go through. What a comfort that is to me!*”

After the procedure was over, I followed that up with, “*So now we are one step closer to getting this show on the road. I know I can do this – I only pray it will be successful.*”

As a last outing before going back into the hospital, Jay and I spent two days on a road trip in Iowa where we went to the horse races at Prairie Meadows in Des Moines and then visited the town of Pella the day before the start of their annual tulip festival. When we got back to Omaha, Erin set up a web site for me at www.livejournal.com to make it easier for us to let friends and family members know what was going on during the transplant without having to write individual letters or emails. We highly recommend using an on-line site such as this one or Caring Bridge (www.caringbridge.com) because it took a lot of

pressure off all of us. Such web sites also allow family and friends who log on to leave comments that helped us a great deal.

In my first entry to the livejournal web site on April 20, 2004, I wrote, *“Goliath should now be called Gostubborn, as he is officially ‘chemoresistant.’ So what do I do now? I have already beaten the odds several times over since all of my early prognostic indicators said I should be quite well by now. I figure that means it’s my turn to beat the odds again, only this time in the plus column. Please keep those thoughts and prayers coming, even if I can’t respond to each and every one of you. Your cards and prayers have allowed me to keep my courage and faith and hope going during a time when I might well have folded up my slingshot and raised the white flag.”*

One lovely event that helped me prepare for the transplant came by way of a dear friend from college whom I regularly corresponded with but hadn’t seen in thirty-four years. She sent me a large smooth stone with a labyrinth etched on one side that had been given to her by a cancer survivor. Along with the stone, she sent a photocopy of a chapter from the book *Kitchen Table Wisdom* by Rachel Naomi Remen, M.D (pp. 151-153). In that chapter, Dr. Remen tells of a ritual she uses for cancer patients in which she asks people who are “connected to them through a bond of the heart” to meet with them right before they begin chemotherapy or radiation or surgery. The patient brings an ordinary stone big enough to fit in the palm of the hand to the meeting. Each invited person holds the stone in turn while recalling a time in life when he or she faced a crisis or difficult situation and what personal quality most helped them make it through. They then speak directly to the patient, saying something like, “I put determination (or faith or whatever attribute helped them) into this stone for you.” When each of their gifts has been given, the patient is free to take the stone to the hospital to keep nearby and hold when things get hard.

Because of my imagery of using stones to kill Goliath, my friend rightly thought this type of ritual would be particularly meaningful for me. In her letter accompanying the rock she wrote, “I chose this rock to be a symbol of connections throughout life’s journey. As you look at the curves and turns in the labyrinth, I hope you can feel our connectedness. Imagine walking in partnership, in love, with those who treasure you for all that you are. Let that bring you courage and strength. There are no barriers and there

are no dead ends in this labyrinth. The path is toward the center, where there is wholeness. So, I give you ‘connectedness.’ May you receive it when you need it most, as you have given it to me through the years.”

Knowing I had many other friends who lived too far away to participate physically in such a ritual, I copied the book chapter into my livejournal web site along with the following request, *“Many of you have asked if there was anything you could do for me. Well, here’s your chance. Anyone who would like to participate can send me your story and the personal quality that helped you at the time so I can put it onto my labyrinth rock that I will take to the hospital with me. Please don’t feel obligated in any way, especially if you are one of those people for whom this would be difficult. I will still know you care.”*

The results were both uplifting and gratifying. One friend wrote about a time in college when she had to have a surgical procedure for which she was told she had a fifty/fifty chance of surviving. She wrote, “With a strong faith and hope I recovered, finished college, and have had so many wonderful opportunities and blessings. I therefore put the gifts of faith and hope in your stone.” Another friend put the gift of “love” into the stone and talked about a time he had considered suicide and said I was the one who cared enough to reach out and convince him not to do it. It’s difficult to express just how much comfort I received from this ritual, but it meant so much that I have since conducted similar healing ceremonies for two other friends. One of them told me he found his rock so comforting that he even slept with it!

On May 6, 2004, I was given an infusion of Rituxan and the first shot of growth factor to stimulate my bone marrow to pump stem cells into my bloodstream. Even though I was frightened about what was ahead of me, I also knew from experience that I would feel much better once we finally got the transplant procedure going. When we got to the treatment center that day, I happened upon a woman named Jan whom I had met in the treatment center early in my illness. She had just gone through a stem cell transplant one month before, and I was amazed at how good she looked. Her spirits seemed high as she told me it hadn’t been as bad as she had feared. She was sixty seven years old, ten years older than I was, and she assured me that if she could do it, so could I. It’s been said that a coincidence may be God’s way

of acting anonymously in your life, and I feel strongly that my meeting with her that day was no ordinary coincidence. I needed some hope right then, and I believe God sent it to me through Jan. I asked her how it felt to be a messenger from God.

During the Rituxan infusion that day I wrote in my journal, *“I feel sure that the tumor has grown considerably during these last couple of weeks without any chemo, but a miracle doesn’t require a small tumor, nor does it follow the regular rules and statistics. I believe with all my heart that a miracle could still happen and I could still get well and use all of this experience to help others. Thanks, God, for giving me that hope and for the faith I have been asking for through people like Jan – my prayers have been answered.”*

Because I had already been given so much chemotherapy, my bone marrow couldn’t produce stem cells as quickly as a normal person’s would have. It therefore took longer than I expected to collect enough cells to safely start my high-dose chemotherapy. Each day of collection the process took about five hours, which Erin and I were prepared for and weathered fine. What we weren’t prepared for was that each collection procedure removed some of my red cells and many of my platelets, so I required platelet and red cell transfusions on most of those days. For some unknown reason I kept developing hives in response to the platelet infusions, so we ended up spending over fourteen hours at the hospital on the second day of collection and thirteen hours on the third day.

The collection center staff told us they expected the fourth day of collection to yield sufficient stem cells to proceed to transplant, so we started the fourth day thinking it would be our last. We were quite tired by then, so it was a major disappointment to hear at the end of the day that I would need to have two more units of platelets before going home and then undergo a fifth day of collection the following day. I cried at that point and wrote in my journal, *“OK, so I am not a happy camper. I admit it.”* However, for some blessed reason the platelets I was given that night didn’t cause a reaction, and we managed to go home after only a ten and a half hour day. The fifth and final day of collection only took eight hours, but that left us with very little time to race home and pack so I could enter the hospital the following morning to start my first day of high dose chemotherapy.

Traversing the Trials of Transplantation

As fate would have it, Jay and I “celebrated” our fifth wedding anniversary the day I entered the hospital to begin the high dose chemotherapy. I wrote in my journal that day, *“Happy Anniversary to us! I wish there had been more time for us to spend together last night without my being anxious, but that wasn’t meant to be. The main thing to remember is Jay and I love each other dearly and are committed to doing whatever is necessary to get past my cancer and go on with our life together. Jay and Erin and I all had to be up by 6:30 a.m. to get to the hospital by the appointed time. After all my days of dreading the transplant, I awoke with a resolve to start the process and think of it in terms of its ability to kill Gostubborn rather than what it might do to the rest of me. In anticipation of the event I wrote in my journal, “I always need to remember that I am strong and I will be able to make it through this no matter what. Chemotherapy is my best friend right now and my ticket to getting the miracle I am hoping for. I know God is the one who provides miracles, but we need to do all we can to help make them happen. My other important job is to think positive thoughts and maintain hope.”*

One of the first things I did when we checked into our room in Cooperative Care at the Transplant Center was tape up pictures and cards and put out other items various people had given me as reminders of their support. One of the most important of those was a quote Peg had sent me from the prayer often called “Be at Peace” by St. Francis de Sales (see www.appleseeds.org). I taped it to the bathroom mirror so I could read it any time I found myself becoming fearful. It says, in part, “Do not look forward in fear to the changes of life; rather look to them with full hope as they arise. God, whose very own you are, will deliver you from out of them. He has kept you hitherto, and He will lead you safely through all things; and when you cannot stand it, God will carry you in His arms. Do not fear what may happen tomorrow; the same everlasting Father who cares for you today will care for you tomorrow and every day. He will either shield you from suffering or will give you unfailing strength to bear it. Be at peace, then, and put aside all anxious thoughts and imaginations.” The very act of reading that prayer daily gave me such comfort that I now routinely share it with others going through frightening trials.

The high-dose chemotherapy was administered over a six-day period. I actually felt pretty good during most of that time, although I was often sleepy and a bit droopy due to all the drugs like Benadryl, Demerol, and Ativan (one of my personal favorites) that they gave me to prevent nausea and other side-effects of the chemo drugs. Erin was a wonderful caregiver who managed to be encouraging without being overbearing. I rarely felt like eating, but she made root beer floats for me every day that never failed to taste good. We watched movies and read books and played a card game called Royalty, for which Erin rigged up a “travelling box” so we could pick the game up and move it from one location to another without interruption of our game.

As amazing as it sounds, we both look back now with thankfulness for that time we got to spend together. Erin attested to its importance in an article she wrote several years later in which she said, “Time is a funny thing in the transplant world. It is what you are fighting so desperately for more of, and yet what often passes monotonously in waiting rooms in anticipation of the next set of ‘results.’ But time is all about how you choose to fill it. My mother and I unexpectedly found ourselves with time for leisurely conversations and bonafide excuses to ‘goof off.’ We had the kind of time to spend together that grown children and their parents rarely get. Despite the hard, scary and ugly moments, we both remember this time as one of the greatest gifts of the transplant process. Yes, it does give gifts!”

Twenty-four hours after the last dose of chemo, they infused my stem cells back into me. They kept me pretty well sedated, so I don’t actually remember much about the infusion itself or the next few days,



Thawing and Infusing the Stem Cells on Transplant Day

for that matter, because that's when the real side effects started. I did write one entry in my journal two days post-transplant, which said in part, *"I'm expecting to feel a whole lot worse than this in the days to come, but so far it hasn't been too bad. They say the next few days will be the worst, so we'll just have to see."* And see we did, as I started to run a fever and had to deal with real nausea and vomiting for the first time in all my months of chemotherapy. As the fever worsened, I also developed mouth and throat sores. The transplant team was wonderful, and they came up with a remedy for each and every problem that arose. I apparently slept through most of the next few days because Erin wrote in a livejournal entry, *"Mom is in a good deal of pain. They've offered her some narcotics like Oxycodone and possibly morphine, but she's resisting so far and sticking to some 'lighter' pain meds despite the fact that every transplant patient we've talked to has said unequivocally, 'take the drugs when they offer them.' She's the only one who can truly assess her pain level, but I'm planning to get pushier if things persist. If it comes down to a battle of wills, I feel confident I can at least stay awake longer."*

On Day 5 post-transplant, my temperature spiked to 104°, prompting treatment with three additional antibiotics. My lungs also started to fill with fluid, my heart rate shot up to 160 beats per minute, and my oxygen levels dropped precipitously as I went into congestive heart failure. This necessitated a move out of the Cooperative Care unit and into the Oncology/Hematology Special Care Unit of the Medical Center. The move had to be a relief for both Erin and Jay, who felt woefully inadequate and were exhausted from tag-teaming my care in Co-Op. Bless Erin, though, because she would not leave my side. She insisted they move a cot into my hospital room so she could continue to stay with me through the days and nights (an arrangement she dubbed "Co-Op Light"). I don't remember anything about the next three days, but Erin and Jay tell me I received excellent care. They also say it helped and encouraged them to note that the staff didn't seem "overly worried," and noted I wasn't going through anything they hadn't seen before. Erin's livejournal comment about that was, *"That's awfully nice to hear, though it certainly doesn't make you want to rush out and have one of these transplants yourself."*

On Day 8 I started to come back around and received the good news from my doctors that heart failure caused by something situational like high-dose chemotherapy had a "decent" chance (can a chance

be “indecent”?) of clearing up on its own once the drugs were cleared from the patient’s body. Happily, that was the case for me. It makes me smile now to read the end of my livejournal post for that day: *“All in all, if I didn’t know I had cancer and congestive heart failure, I’d think I was doing pretty well.”*

However, that was followed by a few days of being truly miserable due to painful mouth and throat sores, for which I finally did ask for morphine. I also had a dreadful and prolonged case of diarrhea, for which I will always be thankful to the makers of Imodium, Vaseline, and baby wipes.

My blood counts started to inch back up on Day 9, and I was gradually weaned off oxygen. This afforded me the luxury of being able to disconnect myself from the heart monitor long enough to go to the bathroom in what Erin dubbed the “big girl” potty and wash my hands with soap and water in the real sink. As Erin and I wrote in our livejournal entry that evening, *“Small pleasures make big improvements in the transplant world.”*

Day 10 post-transplant was Memorial Day, so Erin went out with friends for some much needed R and R and turned me over to Jay, who had the day off from work. Because of the holiday, the hospital was relatively free of outpatients and visitors, so he was able to take me for my first “outing” in a wheel chair, as long as I wore a mask and gloves. It was too cool to spend much time outside, but we roamed the nearly empty hospital halls, and Jay made the time fun for both of us by creating “indoor wheelchair games.” These included “wheelchair shuffleboard,” in which he pushed me down the hall and then tried to let go at just the right time so my chair would stop inside a large circle embossed on the hallway floor. I wrote in my livejournal entry that night, *“Most of all, he made me laugh, and it felt really good. Happy Memorial Day! Next year I plan to go on a picnic. It’s as simple as that!”*

The body is an amazing machine. By Day 12 post-transplant my blood counts had risen enough that I no longer needed daily transfusions. On Day 13 an EKG and electrocardiogram amazingly showed my heart function had nearly returned to what it had been pre-transplant. I was still being treated with three different cardiac drugs, but all of us were ecstatic, especially considering that my cardiologist had told me not to be disappointed if it took much longer to see significant improvement. I took a shower for the first time in days, strolled up and down the hospital corridors wearing my “Miracles Happen” button, and put

my wig on for the first time since I had entered the hospital. I then proceeded to “twiddle my thumbs” as they went through what seemed like endless paperwork before dismissing me from the hospital.



Happy Smiles of My Transplant Coordinator and Patient
Liaison the Day I Left the Hospital

Reentering the Realm of the Real World

Returning home was both exhilarating and frightening. The first thing I did was walk all around the house reintroducing myself to the old familiar objects. I freely admit that type of behavior sounds strange now, even to me, so perhaps I should try to blame it on all the medications I was still taking. More likely it was just a normal reaction for a self-proclaimed “namer of objects” like me, but it felt wonderful to be able to say, “Hello, bed,” “Hello telephone,” “Hello television,” etc. Yet, as thrilled as I was to be home, I felt insecure at the same time about leaving the safety of the hospital with its 24/7 medical staff who always knew what to do if something went wrong. I’m sure Jay and Erin were also happy not to be camping out at the hospital any longer. They never voiced it, but I can only imagine they were equally unsure about being left solely in charge of my care.

At my appointment with Dr. Vose two days after leaving the hospital I was feeling so good I asked her whether I should start back to work half-time. She dispelled that notion very quickly by saying I was “most definitely not ready for that for a couple of months.” She did, however, give me “doctor’s orders” to go out and celebrate with my family that night. The next day I realized how right she had been about holding off on work because I was exhausted and perfectly content to sit around the house as a self-

proclaimed “slug” for the whole day. I wrote in my livejournal entry that night, *“I think I needed that reminder that I am not a Superwoman, nor is there any reason for me to try to be one.”*

After my adrenaline-filled happiness of the first few days at home, Dr. Vose’s nurse called to say the routine blood counts they were doing every few days showed my neutrophil count was quite low. That put a damper on my euphoria and worried all of us because of the danger of infection, but the count came back up on its own in the next few days. By that time my platelet count also had risen enough that they could safely remove the second catheter inserted through my chest wall without risking a major bleeding episode. True to form, I spent some time worrying about having the catheter “pulled out”(as they put it) without anesthesia, but it turned out to be a relatively simple and pain-free event. In the end, I considered it one more indication that my life was heading back toward normal.

The final leg of Dr. Vose’s treatment plan was to let me heal for a month or two after the transplant and then start the radiation treatments of my abdomen. Just as I had been before starting chemotherapy, I was very nervous about receiving radiation. I wrote in a livejournal entry to my family and friends, *“I know I will have some side effects from it because it will be directed into my abdomen and that messes up one’s whole digestive tract. However, it’s a small price to pay for the potential benefits. We have never hit Gostubborn with radiation yet, and many lymphomas are quite sensitive to it. The important thing is my doctors and I will then have done everything possible to ensure success. The rest is going to have to be up to God.”*

I vowed to maintain a hopeful attitude and give thanks for every day I was alive, but the closer the time came to start radiation, the more apprehensive I got about having yet another different and “scary” type of treatment. To my great relief, Dr. Charles Enke, my radiation oncologist, was an exceptionally kind and caring person, as well as an extraordinarily competent physician. He spent over an hour explaining the process and reassuring me that he would do everything in his power to minimize lasting damage to my abdominal organs. At my second appointment, he ordered a CT scan to locate any tumors large enough to be visible. The technicians also tattooed three dots on my abdomen to indicate exactly where to direct the radiation beams.

When they had finished and Dr. Enke came back in to talk to me, I gathered up all my courage and asked him if he had seen any “big old tumors in there.” He took the time to usher me into the projection room and show me what my abdomen looked like then vs. before I started my chemotherapy treatments. My first reaction was astonishment at just what a monster Goliath had been to start with. This was quickly followed by overwhelming thanks at seeing the current CT scan, the first one in nearly a year that failed to show any obvious tumors. Dr. Enke was quick to say it didn’t mean for sure that the cancer was gone, but it was the brightest ray of hope I had been given in a very long time. I told him I would hug him if it wasn’t inappropriate to do so. He just smiled and said he didn’t think anyone would mind. Several years later, I happened to run across him at the Medical Center and told him once again just how much his kindness had meant to me. I believe if physicians could only understand just how much impact even small extra gestures like that can have on their patients, they would do them more often.

On July 15, 2004, I started the first of my twenty-three radiation treatments. They were given every Monday through Friday for nearly five weeks. I tried hard to remember to think of radiation as my new best friend in my fight against Gostubborn rather than dwelling on what detrimental effects it might have on the rest of me. Despite all my apprehensions ahead of time, I had very few noticeable effects from the radiation treatments. The one Dr. Enke was most concerned about was nausea and I had also been warned there might be some burning of my skin, but neither of those turned out to pose much of a problem. The main noticeable side-effect was fatigue, which I had been prepared for. It was certainly not debilitating, but it did make it much harder for me to work during that period of time. This was significant, in that I needed to write two grant proposals for which the deadlines were looming. Each time I started to panic about whether I could finish the proposals in time, I thought of my mother. Throughout my life she used to say, “You have never failed to meet a critical deadline yet, so you probably won’t this time either.” What a wise woman I was blessed to have for a mother!

On July 31, halfway through my radiation treatments, I wrote a livejournal entry that I entitled Celebrate the Day! It said, “*One year ago today my doctor told me there was a large mass in my abdomen. I’m not celebrating that per se, but rather the fact that this last year is over and the next one*”

still holds hope for me. But more than that, I am celebrating the fact that I have learned so much this last year. I have gained a newfound sense of my belief in God and my relationship to Him. I have learned that I am a lot stronger than I ever thought I could be, both physically and mentally. And finally, I have learned that I have the most incredible support system I could ever have asked for.”

I didn't write another livejournal entry until I was nearly finished with the radiation treatments and Erin had left us to go back to school. That entry said, *“This last couple of weeks has been a veritable whirlwind of activity for me – to be sure I had no time to think of myself as a sick person. I turned in the first draft of one grant proposal yesterday to a local committee that will decide whether it is acceptable for national review. I know I still have many hours of work to do on it before it leaves for good, but getting the first draft finished is a major milestone I was so afraid I would not be able to accomplish. Today I will be having my twenty-first radiation treatment and there will only be two more after that. I can honestly say that once again the anticipation was way worse than the actual treatment. I'm just so thankful to have been given a strong and healthy body to start with that has seen me through this last year. All of you have also been instrumental in seeing me through. Please accept my humble thanks”*

Reaching for the Refuge of Remission

“Cure” is a word oncologists rarely use, so “remission” is the magic condition we all strive for. I was told a couple of days before starting radiation that I would have to wait about a month after it was completed for my official post-transplant PET scan that would determine whether Gostubborn could indeed be renamed Gone. That pushed the long awaited unveiling of the results back from the end of August as I had expected to the middle of September. The night I found out about the delay, I wrote in my journal, *“Did I mention before that patience is one of the lessons I think I am supposed to be learning from this experience? Well, I guess this is just another page in my patience workbook.”*

So once I was finished with radiation I entered yet another waiting period. I gradually gained back my strength and energy and was thrilled with each baby step that took me closer to the feeling I might someday become healthy again. As the intervals became longer and longer between visits with Dr. Vose,

Dr. Enke, and my cardiologist, my mantra became, *“Each and every day is a gift from God and I will not ruin it by worrying about what might happen tomorrow.”* At one point I found a small lump in my chest and quickly called the Medical Center. I saw one of the transplant PA’s, who told me it wasn’t in the right position for a lymph node, nor did it feel like one. She felt it was most likely scar tissue from the placement of my catheter rather than anything to worry about. What a relief!

A month after finishing the radiation treatments, I got a much more horrific scare when my friend Peg called me from the hospital. After nearly four years of “remission” from her lymphoma, she had developed what she described as “the worst headache imaginable.” The doctors had performed a CT scan of her head and found a tumor in her brain that turned out to be lymphoma. The news was devastating, not only because I was terribly afraid that my dear friend and most avid supporter might well die, but also because it took the magic out of the word remission.

Thankfully, I was wrong about Peg’s prognosis. She underwent twelve weeks of chemotherapy, some of which was infused through a special port directly into the fluid surrounding her brain. Dr. Vose then told her she would need a stem cell transplant, but Peg told me she didn’t plan to go through with it after walking with me through mine. My immediate response was, “Of course you will, or I’ll have to come over there and kick your butt! There’s no way I am ready to lose you from my life.” I then put my ever faithful prayer patrol on duty for Peg’s recovery. She not only had the transplant ten months after mine, but is still with us today – another of Dr.

Vose’s miracles. Now every year when we have our annual checkups Peg and I beg Dr. Vose to take us as her “Show and Tell” to the annual oncology meeting in Hawaii. Peg even bought matching leis for the two of them to wear on the trip, but so far it’s been no deal on that one!



Dr. Vose (left) with Peg in their Matching Leis

In the middle of September, four months after my transplant, I finally had the blood work and scans to determine whether I was truly in remission. The closer the time came, the more nervous I became, but also the more excited to finally know if everything we had done was enough. I waited with cautious optimism for my appointment with Dr. Vose to get the results, but unfortunately she still didn't have a clear answer. The scan report said there was some "residual activity" on the PET scan and a "questionable mass" on the CT scan, although both of them were significantly decreased from what they had been pre-transplant. That night I wrote in my journal, *"Dr. Vose said she was pleased with the result, but I imagine she would be a whole lot less pleased if she were the patient. Naturally, I wanted the tumor to be gone, gone, gone and see treatments behind me and some smooth sailing ahead. But that's not the answer I got, so I guess I need to just continue to forge ahead."*

As required by a study protocol I was taking part in, I was still scheduled to have four more weekly Rituxan treatments. I didn't see how they could do much good, considering I had already been given so many doses before, but Dr. Vose explained the antibody had a much better chance of being effective now that any tumor tissue remaining was so much smaller. She told me her plan was to do the scans again two months after the last Rituxan treatment. As I took in the fact that meant I would have to spend another three months chasing the illusive butterfly of remission, I wrote to my livejournal supporters, *"The happy part is that these treatments won't cause my hair to fall out again or my blood counts to get dangerously low, so I can lead a more normal life. Sorry I couldn't give you truly happy news, but Jay and I think it could have been a whole lot worse so we are trying to look at the bright side. This just means it's time for me to put on my battle gear again and go back after the beast."*

While taking only the Rituxan treatments, I was able to go back to work full time, allowing me to feel more "normal." Another major boost to my work life was a decision by the National Institutes of Health to allow me to wait until February to submit my grant proposal to them rather than having to do it in October. Upon hearing of their decision, I wrote in a livejournal entry, *"It is so nice not to have that constant worry hanging over my head. Instead, I am focusing my energies for the moment on fighting against the last remnants of Gostubborn, who is now either Gotiny or maybe even Gone. With all of your*

help, I am not even close to giving up. I am feeling good for now and continue to gain my strength back. Thanks to all of you who continue to pray for me. I just know that is one reason I am able to keep living each day as a blessing rather than one of worrying about how many more I will have. God has so richly blessed me with the people in my life. Thanks for being one of them.”

At the end of October, five months after the transplant, I quit wearing my wig as one more symbol of wellness. A month and a half later I had another set of blood tests and scans. Then on December 8, 2004, Dr. Vose finally told me I was “in remission” when the PET scan that measures tumor activity (the seventh one since my diagnosis) was finally read as “normal” – oh that glorious word! Erin even baked a celebration cake for me when she came home for a visit.



The only blemish on an otherwise wonderful report was a couple of new “spots” in my lungs on the CT scan. They didn’t show up on the PET scan so they didn’t appear to be tumors, but Dr. Vose said she would need to order another CT scan of my chest in two more months to make sure they hadn’t grown. Otherwise, she wouldn’t need to see me again for six months, a wonderfully exciting and yet kind of scary thought. I had spent so long under her constant care that I didn’t feel quite ready to be out on my own. I wrote in my livejournal entry that night, *“I am still not out of the woods by far, but instead of crawling through the underbrush, I feel like I’m now following a well-defined path that will lead me toward the light.”* I asked Dr. Vose what the chances were that the cancer would come back. She, of course, declined to give me a number, but she did say that most recurrences come in the first year to year-and-a-half post-transplant. That meant every month that passed without a recurrence made my chances look a little better. As a kind of insurance policy, we decided to leave my chemotherapy port in for at least a year.

As the time approached for my one year transplant checkup, the thought of having scans again was scary, but I just kept repeating, *“Every day I am in remission is a gift from God. It would be so wrong to waste it worrying about what could happen next.”* Thankfully, I didn’t worry too much about it because

it would indeed have been wasted worry. My scans and blood work all said I was still in complete remission. When I asked Dr. Vose what she would do if she were the patient, she said she would probably have her port removed. So, that is what I did. Yet another sign that I truly was “past the transplant” was taking off the medical alert bracelet I had been told to wear for the first year to warn other doctors that I shouldn’t receive blood products unless they were specially treated. Then the crowning experience for the microbiologist in me was initiation of what I referred to as my “baby shot” series. This was necessary because the high dose chemotherapy given during the transplant decimated many of my “memory” white cells that had been protecting me over the years from infections such as polio, tetanus, and diphtheria for which I had been vaccinated as a child. We therefore had to “retrain” my new immune system to recognize these microbes and ward them off.

On May 22, 2005, we celebrated what is known in the transplant world as my first “2nd birthday” because it marked the day I was given back my stem cells and got a second chance at life. I received a number of cards and small gifts to mark the occasion, the most precious of which was life itself. One year after the transplant also marked the time when I could begin training to become a peer support contact for the National Bone Marrow Transplant Link. I decided this was an excellent way for me to “give back” or “pay forward” the kindnesses of the people who called me when I was so scared before my transplant. I knew firsthand how much it helped to talk to someone who had “been there” and was now successfully on the other side. To date I have celebrated eight “2nd birthdays” since my transplant. How happy is that?

It’s hard to describe why I wrote this book, other than to say I felt compelled, even during the darkest days of my illness, to find a way to use my experience to help other people. With that in mind, I have included in the remainder of these pages some of the lessons I learned and the counsel I would pass along to those who might find themselves in the midst of the fray. Although I can’t take your disease away, I hope I can somehow help make it more manageable.

LESSONS SHARED BY ONE WHO HAS BEEN THERE

Acquiring the Assets of Assertiveness

In his “Letter to Cancer Patients” at www.blochcancer.org, Richard Bloch wrote, “The biggest and hardest single thing that you will be required to do in the entire battle is to make up your mind to really fight it.” He goes on to say, “You, personally, must find out all you can about your disease...And remember, this is your life. It isn’t your doctor’s, it isn’t anyone else’s. If you want help, you had better help yourself first.” He suggests that if you don’t relate well or have faith in the first doctor you see, you should find another one. In the end you should, “find the most skilled specialist who believes he can do the most for you...Then go place all your faith and efforts with this individual to help him accomplish what he has set out to do for you.”

Similar advice was given by Larry Burkett in his book *Nothing to Fear – The Key to Cancer Survival*, in which he wrote, “In the final analysis, no medical doctor is really responsible for your health; *you* are responsible for your health. Doctors may help guide, give alternatives, advise, and administer whatever therapy you choose, but it’s *your* body, and you must make the final decisions. If you forget that you’re the one responsible for your own health, you can be overrun by the medical system very quickly.” (pp 11-12) He then added, “You have a specific and designated job, and that is to get over the disease you have. Stop worrying about pleasing other people and doing what they want you to do...that includes doctors. If your caregiver is doing something you don’t agree with and you’re afraid to speak up for fear of irritating him or her, you’re absolutely wrong. It’s your life. You make the decisions.” (pp 135-6)

These were such important words for me to hear as a cancer patient. Although I am very good at mounting my white charger and fighting for the needs of others, I’m a wimp when it comes to bucking the system to accommodate my own needs and wishes. For example, when I went in to have my first diagnostic PET scan, the technician explained that I had to remain perfectly still during what, at that time, was a forty-five minute procedure. I was so nervous about what the scan might show and uncomfortable

about being inside a tube-like apparatus that my whole body was literally shaking. I knew I would need to use my relaxation and imaging techniques to calm myself enough to hold still for such a long time, but relaxation proved almost impossible because the technician was playing rather loud country music. I wanted to ask him to turn it off, but was afraid to interrupt the test. Instead, I remained silent and tried unsuccessfully to block the music out of my head. As crazy as it sounds, even to me now, I also failed to ask him to turn it off for my second PET scan because I liked him and he seemed to like me and I guess I didn't want to ruin our "karma." I desperately wanted the scans to show that Goliath was gone, and all good patients know that our relationships with our scanning technicians determine our results. However, by the time I went in for my third PET scan, I had figured out that karma wasn't working for me anyway, and I finally found my voice. I wrote in my journal while waiting for the scan, *"This time if there is loud country music playing in the room, I'm going to ask him to turn it off. If my insurance company and I are paying \$5,000 for each of these sessions, I should be able to ask that much. Hopefully, the new Martha is learning that I can make simple requests like that without making me a thoughtless, bad, or selfish person."*

Thankfully, as time went on I did learn to become more and more assertive about my medical care. Although she was exceptionally competent and completely professional, I wouldn't have described Dr. Vose as a warm fuzzy person. At first that was hard for someone like me who craves touch and thrives on personal interactions. Although she never spoke harshly or reprimanded me in any way, I somehow felt hesitant to ask too many questions for fear of taking up too much of her time. I knew she had many other patients and limited time for each of us, so at first I practiced my questions before my appointments in order to make them as few and succinct as possible. However, as I read books like the ones quoted above and became psychologically stronger, I also became more comfortable with Dr. Vose, allowing me to take a more active role in my care decisions.

One time I went in for blood tests to determine if my counts were high enough for Dr. Vose to order my next scheduled dose of chemotherapy. That afternoon I received a call from my case manager saying my neutrophil count was only half as high as it needed to be. That meant I would have to wait another

week and have it tested again before seeing Dr Vose. The pre-cancer Martha would simply have done what I was told, but I felt strongly that it was important to have the treatment as soon as possible. Therefore, I told the woman *I wanted* (strange words for me) to see Dr. Vose the next day anyway, and Dr. Vose agreed. I prepared a little speech about how I had great confidence in her abilities and trusted her to make good decisions, but *I needed* (there it was again) to understand more of the logic behind what we were doing so I could have more hope it might work. I became very nervous before the appointment and wondered what Dr. Vose's reaction would be, but after all my worrying, she kindly sat down and thoroughly answered all my questions. Together we decided to wait three more days instead of a full week to check my counts again, with the hope we wouldn't have to delay the treatment for a whole seven days. Happily, when we checked it on the third day, my neutrophil count was just barely high enough to start the treatment, and I found out later that Dr. Vose had written in her orders I could start it even if my counts were slightly lower than the normal minimum. This experience affirmed to me that she had not only listened, but cared about the fact it was critical to my mental well-being not to wait a day longer than absolutely necessary to hit Goliath again.

Once I found out it was all right for me to voice my needs, and that Dr. Vose heard them and was concerned about what was important to me, I realized any communication problems I might have perceived initially were mine, not hers. After that, I found it much easier to talk to her and ask my questions without becoming anxious. I even emailed her twice for advice when I had to make "best-guess" decisions about whether I would be able to fulfill my upcoming teaching assignments and/or submit grant proposals on time. I still apologized profusely for each intrusion on her time, but she always answered graciously and as honestly as she could. As I look back now on the whole experience, I know it was vital for me to learn to assert myself and take care of my needs. After all, it was *my life* on the line.

Expelling the Expectation to be Extraordinary

When I was diagnosed with cancer, I expected myself to be a kind of superwoman who would "do it better" and "bounce back faster" than other mere mortals. For that reason, I expected the outpatient

surgery for collecting the biopsy tissue and putting an infusaport into my chest would be “no big deal.” Two days after the surgery, I was scheduled to introduce the featured speaker from St. Jude’s Hospital at a half-day seminar I had been in charge of planning several months before my diagnosis. Because I was the one who had invited the speaker, I felt my introduction and presence for her talk were essential. When it came time, however, I simply couldn’t pull it off. I didn’t have much lingering pain from the procedures, but the anesthesia and overall shock to my body had been too much. In the end, I decided to stay home to rest and prepare myself for starting chemotherapy the following week. And guess what? My colleagues filled in and entertained and introduced the speaker without me. It all went off swimmingly while Martha, the self-supposed essential element, lay around recuperating. I learned from that experience that I was definitely not a superwoman, but more importantly, that I didn’t need to try to be one.

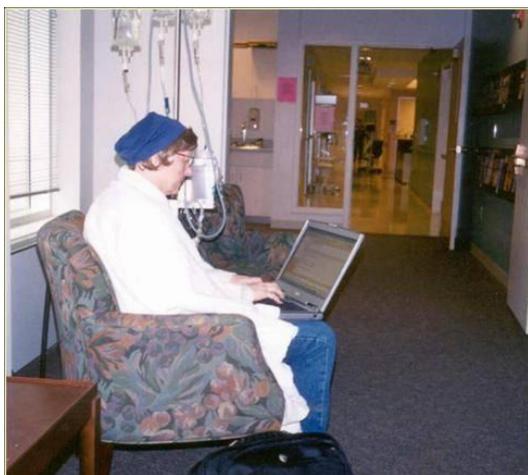
I would like to say I only needed that one lesson on unrealistic self-expectations, but that would be a major falsehood. Nobody else was asking me to be extraordinary, and I knew the world would continue to turn without my help, but I still felt the need to excel as a patient. I vowed I would walk up the three flights of stairs from the parking garage to the treatment center instead of taking the elevator each time I had an appointment just to prove I could still do it. I saw no reason why I shouldn’t be able to continue to be the main caregiver for my ninety-two year old Aunt Calotia, who lived alone and depended on me.

I managed all of this pretty well for a while, but eventually my energy level started to drop, and it became harder and harder to keep up. On Easter Sunday that year I wrote in my journal, *“I feel bad today for not even sending Aunt Calotia an Easter card. That’s not like me, and I could so easily have done it. I have sorely neglected her lately.”* Similarly, I knew my mother-in-law was struggling at that time to take care of my father-in-law, who was in poor health. I wanted to be there to help them, but sometimes I couldn’t seem to muster the energy. One night I wrote, *“Right now I feel too tired to try to make everyone else happy. That’s not a good excuse, but it’s the only one I’ve got.”*

When it came to my job, I also expected myself initially to continue working any time I wasn’t at the hospital having tests or receiving treatments. But inevitably that also became harder and harder to do.

One day after a chemotherapy session I wrote, *“I don’t feel bad today, but I can certainly tell I’m not at my best. I am going to try to work, but the time may be coming when I just won’t be able to do it anymore.”* I immediately followed that up, however, with, *“Oh, come on now, Martha. Are you forgetting what you’re made of? Get back in that ring and keep fighting. You’re not down for the count yet!”*

An interesting side-effect of my drive to be “the best cancer patient ever” was that people kept complimenting me on how well I was doing and how “good” I looked. My wig looked so realistic that a number of people commented, “Well, at least you didn’t have to lose your hair.” Initially those comments made me feel good and I was glad to hear I was making such a good showing of it. But after a while, I started to realize I was tired of people telling me how “good” I looked when in reality I felt pretty miserable. After my fourth round of chemotherapy, I wrote, *“Everyone keeps telling me how well I am handling the chemo and how lucky I am that it’s been so easy for me. It is true, and I know I am incredibly lucky that it’s been easier for me than for many people; but I don’t think there is such a thing as an “easy” chemotherapy experience. Just because a person doesn’t carry on about it doesn’t mean it’s easy for them. I don’t want attention and sympathy so much, but sometimes I get tired of trying to be brave and strong all the time. Thank goodness Jay is very good about holding me at those times so I don’t have to be brave and strong alone.”*



Working During a Chemo Treatment



Looking Too Good? in my Wig

One day when my blood counts were very low, I decided to spend the whole day working calmly from home on a manuscript I was writing. However, in the middle of the afternoon the Dean of the Medical School called an “emergency meeting” for all faculty in my department. I felt it was necessary to go for that, but when I got there I found the “emergency” was a ten-minute announcement that I could easily have learned about over the phone. Since I was already at the University, I decided to stay and read over the dossiers of faculty members I had to evaluate as the designated Chair of the Rank and Tenure Committee. I was determined to have all of the dossiers finished before leaving for the night; but by six o’clock, I knew I was too tired to do justice to the last ones and left feeling very discouraged. When I arrived at home, there was a phone message saying Aunt Calotia had an ulcer on her foot and I needed to buy new slippers for her. Jay wasn’t home yet, and there was a second message from his mother saying she needed help taking his father to the hospital. That night I wrote, *“Sometimes I think all of this is just too much – when is there time to take care of me?”*

The next day I became very anxious about what I perceived as the impossibility of resting and taking care of myself while still accomplishing my work goals and writing all the thank you cards I felt I owed to the wonderful friends who were doing so many nice things for us. At the end of the day I wrote, *“I think I need to let myself take a little time off to grieve for my situation and do some self-pampering and self-care. I need to give myself permission to be sick, and sometimes even selfish. There is no reason I have to be Superwoman and make it through chemo ‘the best anybody can’. I know that in my head, but am finding it very hard to give myself permission to be anything less.”*

At the next Rank and Tenure Committee meeting, I gathered up my courage and told the other members I wouldn’t be able to chair the committee as planned. I ended up being proud of myself for saying “no” and will always be grateful to a dear friend on the committee who stepped up and took over in my place. Once again, the world didn’t stop just because I stepped down.

Deciding I didn’t have to be the best cancer patient ever was a major step in my journey to become what my counselor called a “recovering perfectionist.” My daughter Robin came to visit for several days not long after my declaration of independence from the Rank and Tenure chairmanship. When she left, I

suddenly realized it had been a whole week since I had even written anything in my journal. My first thought (coming from the Perfectionist side I still fight to this day) was that I needed to go back and try to reconstruct my thoughts and get them all down (in order, of course) so that my journaling would be “right” and “complete”. Instead I wrote, *“HOGWASH! There is no right way to do a personal journal, and even if there was, I don’t have to follow it. I don’t need to be perfect at all. I just need to ‘be’, plain and simple. I think this is one of the lessons I am supposed to learn from all of this.”*

Wallowing in the Wasteland of Worry

In *Nothing to Fear*, Larry Burkett makes the irrefutable statement, “Cancer not only has a bad reputation but also has a very bad track record, because many of the people who are diagnosed with cancer don’t survive it. But ... the people who have perfect health don’t survive that either...Nobody lives forever.” (pg 30) Later, when he talks about overcoming worry and fear, he quotes Holocaust survivor Corrie Ten Boom with the wise saying, “Worry does not empty tomorrow of its sorrow; it empties today of its strength.” (pg 129)

I am the first to admit it was as hard for me as it is for most human beings not to worry when faced with a potentially terminal illness. My journals are full of entries echoing fear and literal trembling each time I had to undergo a new type of test or start a new chemotherapy regimen or initiate radiation treatments. In fact, my cancer experience was filled with examples of stewing and fretting over things that either never came to pass at all, or turned out to be much easier than I had anticipated.

A prime example of that came early on as a result of my lifelong fear of having my face covered and not being able to see what is about to happen. Knowing I was somewhat claustrophobic as well, I became terrified as soon as I heard that some people become anxious when they are passed slowly through the tube-like apparatus used in the PET scan machine. Believe it or not, I was far more worried before my first PET scan about spending forty-five minutes in a small tube than I was before my first bone marrow biopsy about having large needles stuck into my hipbone. I even contemplated asking for sedation to help me get through the PET scan. In the end, I did both procedures without medication, and all of my worry

about the PET scan was for naught because the tube wasn't nearly as tight as I had envisioned it, nor was there ever a time I couldn't see out one end of the tube or the other.

So after that first scan, I quit worrying about the actual scanning process itself and instead concerned myself about the numbers I could see on a digital display above me as I passed through the machine. I noticed they increased precipitously as my abdomen passed into the scanning area. Even though I had no idea what the gauge was recording, I felt certain the high numbers were indicating radioactivity due to the presence of Goliath in that area. Finally, I became so anxious about it that I told the technician I was going to try to keep my eyes closed so I wouldn't be able to see the numbers go up when that part of my body entered the machine. And after all my days of distress over those "numbers," he dispelled the myth I had created in my mind by explaining the numbers go up like that even in a person without a tumor because the radioactive glucose they inject before the test always shows up in the patient's bladder!

Another major obsession of mine at that time was a blood test known as the LDH level that Dr. Vose ordered for each of my checkups. The LDH test measures enzymes that generally rise when there is tissue damage caused by something like the presence of a tumor. It is frequently used as one of the prognostic indicators during the initial diagnosis of lymphoma, and then falling levels serve as a measure of tumor regression. I knew my friend Peg's LDH level was exceptionally high when she was first diagnosed. Then it came back into the normal range by the time she finished her first four chemotherapy treatments. I also knew my LDH level was only slightly above normal at diagnosis, so I naturally expected mine to quickly drop back into the normal range if my treatments were working. That never happened, which upset me each time it was tested, no matter how many times Dr. Vose told me not to "put too much stock in those numbers." At one of my appointments in which I asked about it she said, "LDH isn't a very good indicator while you're still getting treatment." My journal comment after I left her office that day was, *"That's easier for her to say than it is for me to do."*

Even when I wasn't poking around in my abdomen trying to tell if there was a lump there any more or stressing about whether the tumor was getting larger or smaller, I tended to become anxious at the end of each chemotherapy cycle that my neutrophil count would be too low to have the next treatment on

time. I knew that having to delay a treatment might give Goliath extra time to regain the upper hand. Because I had a laboratory of my own, I had the wherewithal to perform rather crude neutrophil counts on myself a day or so before my scheduled blood draw. I did that occasionally just so I could be more mentally prepared in case the official counts they performed at the hospital were too low.

One time when my own test count suggested I wouldn't be able to have my treatment on time, I wrote in my journal, *"OK, so my blood counts are really low right now. That just means I need to come up with extra positive thoughts for my bone marrow to start making blood cells really soon."* As if it could help encourage blood cell production, I kept holding the bones in my forearm up to my friends' and coworkers' ears while declaring, "If you listen closely, I'm sure you can hear my bone marrow kicking out little neutrophils as we speak." And amazingly, after all of my worrying, the official count was indeed high enough for my treatment. In fact, only one of my ten treatments had to be postponed due to low blood counts. Similarly, despite all of my worrying each time my counts got low, I made it through each of my chemotherapy treatments without an infection.

In looking back over all of this, I know Corrie Ten Boom was right. None of my worrying helped me in the least, but rather bogged me down in a sea of anxieties instead of allowing me to spend my energies on constructive activities. The one thing I found most helpful during those times of wallowing in the wasteland was to repeat over and over again, "Today is the day the Lord has made. I will rejoice and be glad in it." As I thought about that declaration during one of my braver moments, I wrote in my journal, *"I am determined not to ruin each day I feel good (each one a gift from God) by worrying about what might happen tomorrow. How can I expect God to save me and use me later if I waste these days when He could be using me now?"*

Finding the Fruits of Friendship

I used to tell my daughters that not all friends are equal. Some will be "forever" friends for life and others "fair-weather" friends that come and go, depending on the circumstances. It isn't always easy to tell which ones will be your forever friends until something major occurs in your life. A cancer

diagnosis is one of those thunderstorms that can easily drive the fair-weather friends away, but I also found that even some forever friends understandably have a very difficult time coping with what could be a death sentence.

At first I was perplexed and even somewhat dismayed when certain of my long-time friends completely dropped out of my life. Years later, one of them told me she had wanted to call or see me, but felt too inadequate and worried she might say the wrong thing. I think it's important to take this opportunity to explain to the would-be "forever friends" out there that they shouldn't let the fear of saying or doing the wrong thing keep them away. Sometimes just being there and listening or giving a hug is enough without any words at all. If you have trouble thinking of what to say, you can also let Hallmark do it for you. Some of my dearest long-distance friends regularly sent cards that brightened my days and reminded me they cared and were thinking of me. One childhood friend in particular always included a photo or wrote amusing anecdotes about memories of things we did together as kids and long-time members of the same Girl Scout troop. They never failed to make me smile.

Cancer itself can also bring new friends. I actually first met Peg as a result of her having had lymphoma. I volunteered for the American Cancer Society's "Look Good, Feel Better" program for several years before being diagnosed with cancer myself. Peg had attended one of their classes at a different location during her first bout with lymphoma, and it helped her so much she decided to become a volunteer with the program. She attended one of my classes just to learn more about what the volunteers do, and we were immediately drawn to one another. We ended up becoming such dear friends (the forever kind) that we have continued to volunteer together and I can't imagine what I would have done without her in my fight against Goliath.

A friend once sent me a card that said, "God is so good about sending us the right people at the right time." Peg was one of those people for me. When I first told her the doctor said I probably had lymphoma, she promised to keep a prayer candle lit for me in her home so she would be reminded to pray for me every time she walked by it. When she heard I was gathering stones, she gave me a Lucky Penny set in Connemara marble formed 90,000,000 years ago in Galway Ireland. She told me she chose it

because it would show me that 90,000,000 years ago God already knew I would need a stone to fight Goliath and made one especially for me. On the note she gave me with the stone she wrote, “So, my friend David, I am continuing to lift you and yours every day, and my candle will burn for you as long as you need it. I’ll also help you polish your stones and knead the leather of your slingshot to make it willing and supple to support the artillery!”

Volunteering for the Look Good, Feel Better program also brought another wonderful friend into my life, a cosmetologist named Deb who specialized in head coverings and hair replacement. Little did I know when I first met her that I would need her services myself. Being a proactive person, I decided to go to Deb’s shop a few days before my hair was expected to fall out so she could cut it very short to limit the mess when it started to shed. Deb measured me for my wig and helped me pick out several hats and turbans and something called a face framer, which is a ring of hair to wear under hats. When I got out my wallet to pay for all my purchases, she told me she was giving them to me free of charge. When I protested, she said simply, “These are my flowers for you.” How grateful I am to people like Peg and Deb and so many other “forever” friends for making such a huge difference when I needed them most. I think it’s only fitting to repeat to them here what was written on a thank you card I once received, “God knew what I needed most, and He called on your kind heart.” Bless all of you for answering – He used you in special ways you might not have been aware of at the time.

Reverting to the Role of Receiver

When we are children, we are by nature “receivers” who graciously accept loving care and sustenance from our parents, grandparents, aunts and uncles, teachers and assorted others without feeling guilty or giving a thought to returning the favor. But as we age, most of us discover the joy of giving, and we gradually become the responsible ones who take care of other people. By the time we’re adults, women in particular tend to picture ourselves as the “givers” – the parents who nurture our children, the comforters who shore up our hurting friends, the good Samaritans who deliver casseroles to our ill neighbors, and eventually the caregivers who look after the needs of our own parents.

Cancer is a disease that often necessitates a shift backward. Biopsies and scans, chemotherapy and radiation, blood draws and doctor appointments all take so much time and energy that our focus has to turn inward, putting a halt to the more giving side of our natures. Instead of thinking about others' problems, we are faced with the need to learn once again how to graciously accept the help others offer to us. I had an especially difficult time at first with the reality that everyone else was taking care of me instead of the other way around. I suffered from guilt over not being able to give anything back, and I worried that I was no longer a worthwhile and useful person.

At the beginning of my illness I faithfully kept track of the names of all the people who sent me cards and brought in food. I tried to describe in writing each of the rocks people sent and kept a list so I could thank them properly and know for sure which one came from whom. But all of that became increasingly difficult, and unwritten thank you notes started to loom before me. In short, I found myself feeling more stressed than blessed by the actions of the very people who were trying to help. It was at that point I decided to talk about the problem with a counselor.

My counselor helped me see things differently by explaining that I was looking at giving as a one-way type of dependency rather than the "interdependency" healthy relationships entail. She pointed out I had done my part when others were in need, but now it was my turn to receive. She helped me realize it was all right for me to have needs too. During one of our sessions she handed me a card on which she had written, "We are more loveable in our vulnerability." I taped it to my mirror, where I could see it on a daily basis, to remind me it was my turn just then to be the receiver. As time went on, it dawned on me that when we refuse to let others "do" for us, it deprives them of the very thing we ourselves have taken so much pleasure in over the years – and that isn't fair to them.

Pastor Todd Burpo touched on this same subject at the end of his book *Heaven is for Real* when he talked about the money and other types of aid his family received after his four-year-old son's brush with death. When asked how the outpouring of help had changed their family, his answer was, "See, pastors and their families are usually most comfortable in the role of 'helper,' not 'helpee.'" Sonja and I had always been the ones who visited the sick, brought the meals, cared for others' kids in times of need. We

were adamantly self-reliant – maybe, in retrospect, to the point of being prideful. But that grueling stint in the hospital snapped our pride like a dry twig and taught us how to be humble enough to accept help from other people, physically, emotionally, and financially. It’s good to be strong and able to bless others, yes. But we learned the value of being vulnerable enough to let others be strong for us, to let others bless us. That, it turned out, was a blessing to them as well.” (pg 153)

And so, like Todd Burpo, I had to learn to be comfortable in the role of receiver. Rather than worrying about whether I was being too self-centered or if I had appropriately thanked each person’s contribution, I got better and better in small increments at simply accepting and appreciating my friends’ and well-wishers’ gestures and gifts. And in the end, it made all of us happier and our relationships healthier.

Sharing the Stones of Solace

Once I started telling people I was collecting stones to help me slay Goliath, I was amazed to learn how many people owned rocks that held meaning for them. I was even more amazed at how many of those same people were willing to share their special rocks with me. First, Jay gave me two smooth agates (one for each tumor) from the Grotto of the Redemption in West Bend, IA. He said he had been saving them “for some reason” since he was fifteen, and now he knew this was “the reason.” Robin, my particularly analytical child, gave me a piece from her game of strategy called Pente “to represent the power of your mind over your body.” Erin chose a malachite egg she had purchased with her own money at age nine. As a symbol of their combined love, one couple I had known for years mailed the class ring he had given her when they went steady in high school. Another couple sent me painted rocks they had decorated as keepsakes from the emotionally charged Catholic retreat where they met.

My four-year-old great nephew, who had a treasured rock collection of his own, looked long and hard, but couldn’t find a rock he thought was “powerful” enough to kill Goliath. He finally told his mother he wanted to send me his favorite rock from his collection. A coworker presented me with ten colored glass stones, each one etched with a different word such as faith, hope, trust, and miracle.

Because they were made of glass rather than minerals, I was allowed to hold the one bearing the word “courage” in my hand during that first PET scan that I was so frightened of. All in all, I ended up with rocks that came from at least sixteen U.S. states and five foreign countries. Several rocks arrived by mail from people I had never even met. They had simply heard about my stone collection and were moved to contribute. One of those was from my friend Peg’s brother-in-law who lived in Arizona. In lieu of a stone, he made a soft leather slingshot for me with instructions to “take it with me onto the battlefield.”

At first, I stored my stones in a small round wicker box I purchased at Hobby Lobby because it looked to me like one that could have been used by a young boy like David in ancient Palestine. Each time I went to the hospital for a chemotherapy session, I faithfully carried in my box of stones and set them out on the bedside table to remind me of the people who were fighting my battle with me in prayer. As the stones continued to pour in from my relatives and friends and then some of their relatives and friends, I had to go back to Hobby Lobby to buy a larger version of the same box to house them all. My smaller box then became my “travelling box,” in which I carried different stones with me to each of my chemotherapy treatments.



Word began to get around the treatment center, and some of the employees began calling me the “Rock Lady.” One of the chemotherapy nurses was so touched by my rock stories that she brought me a snail figurine made of rocks. She said her best friend had given it to her for her seventh birthday. On the accompanying card she wrote, “That was thirty-two years ago. Something made me hold onto it for all these years – now I know why.”

My stones provided me with immeasurable comfort, strength and courage, so much so that I kept trying to figure out how I could share those blessings with other cancer patients. Then one day Peg called to tell me about a bible passage she had studied in her prayer group that morning. It came from Second Corinthians 1:3 – 6, and includes the words, “He supports us in every hardship so that we are able to come to the support of others in every hardship of theirs because of the encouragement that we ourselves receive from God.” Those words provided me with the idea that I might be able to help other cancer patients by sharing stones with them.

My idea was facilitated by the arrangement of the treatment area at the University of Nebraska Medical Center, as well as the chemotherapy process itself. The treatment center consisted of two pods of individual patient rooms surrounding a nursing station. Each patient room was constructed of three solid walls to allow privacy plus a glass front wall to allow the nurses to continuously observe their patients. Because chemotherapy is generally administered with bag after bag of intravenous fluids, I had to make frequent trips to the restroom that took me past other patients’ glass-fronted rooms. I decided to start carrying small smooth stones with me, and eventually I got up the courage to stop and present them to some of my fellow patients. A few of them were not at all eager to be interrupted, but others were quite receptive. In the end, I made several lasting friends that way while helping myself pass the long and often tedious hours spent at the treatment center.

Once I finally achieved remission, I began a kind of “rock ministry” inspired by a smooth, beautifully colored stone my brother had found on an island near his home. Before he sent it to me for my fight with Goliath, he wrote the word “remember” on one side and drew a small cross on the other. In the package with the stone, he sent a list of things he wanted me to remember during my treatment. It included the following:

- “Remember to look at the world daily and prize each moment.”
- “Remember that chemotherapy is a gift and your best friend.”
- “Remember not to give up on dark days because you can do this.”
- “Remember how many people are praying for you daily.”
- “Remember that you are a non-repeatable miracle and beloved by God.”

Because my brother's gift had meant so much to me during my own battle, I asked him to help me collect and decorate similar stones that I could then share with other cancer patients. To date, I have passed out over 200 small gift bags I refer to as my "rock bags" to other people fighting cancer. Each bag contains a Remember Rock and the list of the "Remember" items my brother had sent, along with the following message:

You are receiving this rock as a special gift from me. When I was diagnosed in August of 2003 with a very large tumor, I named it Goliath and began to think of myself as David, the boy who killed the famous giant. When people asked what they could do to help me, I told them to give me a rock to use in my battle. One of the rocks I received was similar to the one I am giving you. It came with a list of things for me to remember that helped me so much I wanted to share them with you too. My hope is you will keep your rock with you and use it to help you fight your own battle. Good luck to you. Go get 'em!

Martha Nielsen

Cherishing the Comfort of Caregivers

It would be hard to over express just how important the support of family can be to a cancer patient. In one of my early emails to my family members I wrote, *"Thank you all ever so much for your support. I couldn't have a better team on my side, and poor old Goliath only has that one wimpy Philistine to hang out with. Let's face it, the dude is doomed."* Even though both my daughters lived on the East coast and weren't able to come often to spend time with me, they were a constant source of comfort and sustenance for my soul. They faithfully sent cards to cheer me and made phone calls to bolster my flagging spirits. When they did come to visit, we found we cherished our time together even more than we might have before my illness. It was fun to go out shopping with them, when I was able, and do some of the other "normal" things we always had done. However, we somehow did them with more intensity because we didn't know how much longer I would be there for them. I know their visits were sometimes hard on them, particularly when my recovery started to look less and less possible. I will always be grateful to

them for striking a beautiful balance between ministering to me and yet also reminding me they will always “need” me to be their mom.

Throughout my illness, it was my husband Jay who was the real “rock” that helped keep me grounded. He was incredibly patient and kind when I was afraid and I couldn’t have been more thankful for him. At one point I wrote in my journal, *“Jay has been so good about just holding me when I get scared and neither ignoring things or going overboard hovering. He seems to know just when I need some empathy without being oppressive.”* Of course, I knew it wasn’t easy for him to be my caregiver and still maintain a semblance of our former kind of relationship. There were bound to be a few bumps in the road that required me to evaluate what I needed versus what would enrich our connectedness.

During one of my early chemotherapy cycles, Jay contracted a bad cold just when my blood counts were at their lowest levels. He was a bit put off by my paranoia about his every sneeze and cough and my habit of running along behind him with the Purell bottle wiping off everything he touched. Looking back now, I can understand how hard it must have been for a caregiver who only wanted to help to be treated like a pariah. However, at that time and place, the microbiologist in me was bent on using extreme caution. One of my journal entries during that time expressed my dilemma, *“My blood counts have fallen quite a bit already, so I know I need to be careful in the days to come. Unfortunately, Jay seems to be coming down with a cold. I don’t want to offend him by being reluctant to spend time with him, but I can’t let that stop me from taking as many precautions as possible. It’s hard to know how I should act or how much I have to focus on my own health. I don’t want to do that too much, but I also need to do everything I can to give myself the best shot at being cured. I want to get well!!!!”*

As comforting as Jay tried to be most of the time, his role of “keeping me grounded” sometimes required him to suggest I rein in my emotions. One day in particular when things were starting to look bleak, I became overwhelmed by worry and fear of what was to come. I asked God in my prayer time to give me a kick in the butt if that was what I needed. I guess God took me at my word, because that same night Jay told me he thought I was obsessing about my illness. Because that was such an uncharacteristic comment coming from Jay, I wrote in my journal, *“Maybe he is right and I needed to hear it, but I*

struggle so hard to fight against obsessing and most of the time I think I do a reasonably good job. I think part of the problem is I tend to verbalize all my feelings, whereas Jay rarely talks about his. To him, then, it must look like I fret all the time. I need to try harder to be more positive around him. I'm sure it's hard for him to be with me otherwise, and I need him." I did try after that to voice my fears less often, but the following day when I stayed home with low counts while Jay went to work I wrote, *"In some ways it feels good to be alone for a while so I can just be however I am without worrying about inflicting it on someone else."*

Each relationship is different, and each requires open communication to maintain that delicate balancing act between sharing and withdrawing to protect the other person. Sometimes it is difficult for patients not to get so caught up in their own distress and apprehension that they forget how extremely hard the process is on the people who love them. For this reason, I believe it's very important to make sure both patients and caregivers have other outlets for relieving their fatigue and anxiety. It's only as I look back now that I realize how much additional stress Jay happened to be carrying during my illness. It was toward the end of my fourth chemotherapy cycle that his mother called to ask for help taking his father to the hospital. I went to their house with Jay to pick them up but couldn't go with all of them to the hospital because my counts were extremely low. I simply hugged his father instead and told him goodbye before they left. I never saw him again.

Jay father's death several days later occurred right before we found out that I was going to need additional chemotherapy and most likely a stem cell transplant. That left Jay to help his mother make all the preparations for the funeral, look after their financial affairs, and deal with her grief as well as his own with very little help from me. I felt terrible that I couldn't provide more support for both Jay and his mother at a time when I would normally have been a major contributor. However, I realize looking back now that it all fit well into God's plans for Jay and our marriage. The night before his father died I wrote in my journal, *"I keep asking myself why all of this is happening at a time when I can't even go to the hospital to be with them. I wonder if what both Jay and I are supposed to be learning from all of this is just how strong and capable he is. He is doing a wonderful job without any help from me."*

In the wee hours of the next morning, Jay came home from the hospital after guiding his mother through the agony of turning off his father's life support and watching him take his last breaths. My journal entry that day includes, *"Jay has done so very well with all of this, and I am proud of him. I believe it was important and a good thing that I couldn't be there to help him, even though I wanted to. He needed to do it alone, and I needed not to intrude on that. Thanks, God, but I do need to say I'm hoping this wasn't your way of preparing him to learn to live without me for good – at least not in the near future."*

Six months later as we were completing the final preparations for my stem cell transplant, Jay's mother called again from a local emergency room to say she had fallen and broken her hip. This time I was able to go with Jay to the hospital to help him make decisions about her care. Her surgery went well, but she had to recuperate in a rehabilitation center for several weeks before she could return to her home. This meant Jay had to find an appropriate care facility and get his mother situated there at the same time he was helping me get ready to enter the hospital for my transplant.

Shortly thereafter, we were told one of Jay's adult sons needed to have his thyroid gland removed. It all seemed so unfair that I couldn't help but get mad at God. On one occasion I wrote, *"OK, God, I don't care if it is wrong to be angry at you. Even though I know you are in charge and things are happening according to your plan, I can't understand how anything good could possibly come from this. It seems terribly unfair for all of this to be happening to Jay at the same time. I realize there must be a reason, but you need to show it to us if we are supposed to somehow learn from it and use it well."*

One other thing I learned about family relationships from my cancer experience was somewhat unique to the structure of our family. My marriage to Jay was a second one for both of us, and we had only been married for four years when my cancer was diagnosed. During all of our time together, both of my daughters were old enough to be living on their own. Because they lived too far away for frequent visits, I didn't feel they had been given enough time to clearly establish their roles with Jay as adult daughters of a step-father. I loved Jay and my girls so much that I desperately wanted all of them to be close to each other too, but I knew that wasn't something I could "make" happen.

I was particularly worried about having Erin move in to our home for three months to help care for me during and after my transplant. I wondered if having her take the role of my primary caregiver would make Jay feel left out or maybe even jealous of the closeness Erin and I shared. As the eternal “peace maker” in my family, I fretted for days over what might happen and felt I needed to step in and “do



Jay and Erin Bonded Just Fine
Without my Meddling

something” to stave off any potential problems or awkwardness that might possibly arise. Then one night I decided it was a waste of my emotional energy to try to smooth things over and please both of them. I wrote in my journal, *“I guess I have learned, at least a little, to only be in charge of and take care of me while letting everyone else be in charge of their own happiness.”*

That was a big step forward for me, and

happily we all got along wonderfully well. I guess this was just one more time God didn’t need me and managed things just fine without my meddling in His business.

Healing With the Help of Humor

They say laughter is the best medicine, and I certainly found that to be true during my cancer experience. Obviously, there is no way to laugh away pain or fear or bad test results, but in the midst of all those distressing events, humor definitely helped me and my family cope. In her book *There’s No Place Like Hope*, Vickie Girard does a marvelous job of providing cancer patients with practical advice dosed out in little snippets, many of which are light-hearted and charmingly witty. One of my favorites is in her chapter describing some of the dumb things people tend to say to cancer patients. To quote her, “We hear this one all the time and, believe me, cancer patients truly hate this statement, ‘Well, no one knows how long they have. After all, I could walk outside right now and get hit by a car.’ What? Did

cancer patients suddenly become car-immune? This is not a fair analogy. Now, if you were being forced to walk blindfolded down the middle of the expressway during rush hour – maybe then we could talk.”

(pg 78) This is just one small example of why I heartily recommend Ms. Girard’s book to anyone looking to find humor in the midst of a battle with cancer.

In looking back, there were numerous instances in which I used my own humor to help myself and others feel more comfortable with the situation we found ourselves in. For example, when I went to the hospital to have the laparoscopic biopsy of Goliath, I asked the surgeon to do a favor for me. I told him I would truly appreciate it if, while he was working inside my abdomen, he would say in a loud and very stern voice, “Goliath, your days are numbered!” He solemnly promised to do it, and when I went back to see him for my post-surgery checkup, he told me he would always remember me and that experience.

I also tried to use humor, when possible, to help reassure my family and friends. When Erin came to visit just after I started chemotherapy, she had to see me without hair for the first time. I could no longer feel a lump in my abdomen where Goliath had been, so to lighten the mood I asked, “Do you want to feel Goliath? – well, too bad!” I also used humorous signatures in my early email updates to my family, such as “Martha (you know, the one who used to have that big old tumor in her tummy),” “Martha and the Soon-to-be-Eliminated, Poor Old Excuse-for-a-Tumor, Goliath,” and “Martha and her Wussy and Sick Opponent.”

My propensity to name things actually helped us keep a sense of humor at times. When I first started chemotherapy, my infusaport had a maddening tendency to develop clots. Each time this happened, it would delay my blood draw or the start of treatment by over an hour while the nurses cleaned the port out with a clot-busting enzymatic solution. Although it didn’t occur every time, it happened enough that I started calling my faulty port “Persnickety Port.” Thankfully, the clots occurred less frequently over time, so one of my favorite nurses and I decided later on to change its name to “Pollyanna Port,” with the hope the new name would encourage its continued good behavior.

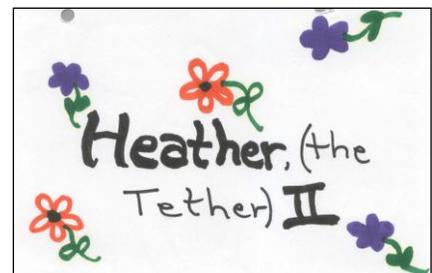
Dear Peg served as a special source of both information and humor during my R-CHOP treatments since she had already “been there” and had come out on the other side. For example, when I noticed a

white line growing out from the cuticle on each of my fingernails a couple of weeks after my first R-CHOP treatment, I called Peg to ask if that had happened to her. She just laughed and said, “Oh sure, you get one line for each cycle – just think like a tree.”

Jay also was great at invoking his dry sense of humor to help us through the hard times. When he took me in to have that first scary PET scan, he asked me where my “test” was supposed to take place. After I had read him the directions, he looked at me in all seriousness and asked, “Have you studied?” Then when my hair was due to fall out any minute after my first chemotherapy treatment, we were invited to his parents’ house for dinner. I hadn’t washed my hair in three days and told him I didn’t want to go because my hair looked “scrummy” (another of my naming words). Without a moment’s pause he retorted, “No worries. If they think your hair looks scrummy, they won’t be so bothered when we tell them it’s about to fall out.”

I knew throughout my illness I could always count on this same kind of humor from Jay. One day, when he noticed an envelope from the American Cancer Society among the solicitations in our mailbox, he inquired, “What does the Cancer Society want from you? You already have cancer!” He also became a favorite of the treatment center nurses by asking them such questions as why we never got a treatment room with a mountain or ocean view and whether we could possibly get a punch card like they give at the pizza restaurant to allow us one free treatment after collecting a certain number of punches. Whatever would I have done without him?

There is also no way I could have done without Erin’s sense of humor. Having been raised in my household, she was well acquainted with and participated in my propensity for naming inanimate objects. When I did my first five-day ESHAP stint in the hospital that required 24/7 infusions of the chemo drugs, she named my ever-present chemotherapy pole “Heather, the Tether.” She made a sign to put on it as we paraded through the hallways. For the second ESHAP treatment, she simply amended the sign to read “Heather, the Tether II.” When she came to be my



main caregiver for the transplant, she continued to help me name various hospital objects in an attempt to make things feel more lighthearted and less scary. For example, the plastic inspirometer she nagged at me to inhale through at least ten times a day to keep my lungs functioning well became “Pneumo” in deference to the spunky little fish in the movie *Finding Nemo*. In further keeping with our *Finding Nemo* theme, we called the decidedly battered and slightly cracked, but ever faithful, puke pot “Gil.”

Finally, I will also always be indebted to a veterinarian friend from church who routinely made us laugh at the comments he left on my livejournal website during the transplant. When I first started to run the high fever after receiving my stem cells, he wrote, “I just thought you should know how I treat canine patients with high fevers – we use ice water enemas. Would you like me to come up there and get your fever down?” Later on, when I reported that my neutrophil count was finally starting to come back up, he quipped, “If you were a dog, we would know you are about ready to chase a ball and lift your leg on a fire plug. If you continue to improve at the rate you have the past few days, I would pat you on the head, give you a Milk Bone, and tell you to go home and rest.” Bless him for his wonderful brand of healing humor, even if it did cause some raised eyebrows on certain of the older ladies in our church who were frequenting the web site.

Struggling with the Strangeness of Steroids

One of the four drugs included in the R-CHOP regimen was a large dose (100 mg/day) of the steroid prednisone that had to be taken by mouth on the first five days of each cycle. For anyone who has never taken steroids, let me explain that although they are amazing wonder drugs that can help many types of ailments, they also have a number of common side effects. These include insomnia, fluid retention, increased appetite, indigestion, mood changes, euphoria, and nervousness. Typically, when people stop taking even small doses of a steroid like prednisone after a prolonged period, they are told to taper the medication dose gradually to prevent the side effects that can occur during “steroid withdrawal.” However, most doctors don’t consider the five-day course of prednisone included with R-CHOP long enough to warrant tapering. I

have decided those doctors need to try taking 100 mg of prednisone for five days and then stop cold turkey to see how it feels before recommending it.

The day after I started taking prednisone for my first round of R-CHOP I wrote in my journal, *I didn't sleep too well last night, but I felt amazingly good when I woke up. I think the Prednisone gives me a kind of high – like the amphetamine diet pills our family doctor gave me once as a teenager, except without the anorexia. It lifts my spirits and makes me feel full of energy.*” The next night I wrote, *I didn't sleep well all last night. I wasn't distressed or anything, just 'awake' for several hours trying different things to make myself sleepy.* By the end of the second day I wrote, *I know there must be harder times coming, but it's wonderful to have sailed through this first treatment so well. One done!*

I continued to feel well and go to work every day for those first five days I was taking prednisone. But about a day and a half after my last dose, I wrote in my journal, *“Today just isn't a good day. I don't feel good physically or emotionally. I am weepy and worried and unreasonably distressed in comparison to how I feel physically.”* By that night I had terrible indigestion pain that kept me awake all night. I described it to my nurse coordinator the next morning as a feeling my esophagus was being eaten away by acid. She phoned in a prescription for the drug Nexium and told me I could use over-the-counter liquid Mylanta for a day or two to soothe my esophagus while waiting for the Nexium to start healing it.

Desperate for quick relief, I stopped at a nearby grocery store to buy some Mylanta on my way to work. I hadn't thought to bring along a spoon to measure the dose, so I just tipped the bottle to my lips and chugged some down in the parking lot. I figured out later, after reading the label, I probably took about three times the suggested dose. It gave me wonderful relief, for which I was grateful, but I had the good sense to measure how much I was taking after that. A couple of days later the Nexium started to work its magic, and I ended up taking it for most of the next year.

A day and a half after discontinuing prednisone during my second cycle of R-CHOP, I wrote in my journal, *“I am starting to feel sleepy and dopey and kind of dumpy. It's just harder than usual to have positive thoughts.”* In trying to explain the feeling more fully to my family, I described it at various times as *“a feeling of hovering discomfort,” “worrying about something I can't quite put my finger on,”* and *“a*

general feeling that things are not well with me.” I decided to call that withdrawal reaction that generally lasted twenty-four to thirty-six hours “*a feeling of dis-ease.*” By the third cycle the withdrawal seemed a little easier to handle, perhaps because I knew what to expect and also because I knew it would probably go away by the next day. Even so, I still found myself being short with people and generally irritable and unhappy. True to form, by the next night I was feeling much more like my old self again. I attended a beautiful wedding and realized at the reception that I had come out of my “post-prednisone funk.” I wrote in my journal that night, “*It sure feels better not to feel so icky.*” Then when enough of the prednisone effects wore off that I was finally able to get a good night’s sleep I wrote, “*We forget sometimes to be thankful for the things that are important but taken for granted. I guess I needed to be reminded*”.

Seeking the Sleep of the Slumberous

Sleeping, or more accurately the inability to do so, was a major concern and source of anxiety for me throughout my cancer experience. It actually started a few weeks before I received my diagnosis. Most of my life I had been blessed with the ability to go to sleep within five minutes of falling into bed at night. I would then sleep well and awaken refreshed in the morning. I had always been particularly thankful to take after my father in that respect, since my mother was a notorious insomniac. But shortly before I learned I had cancer, I started having trouble falling asleep. I also woke up repeatedly during the night. Perhaps I subconsciously knew something was wrong with me, or maybe it was just the result of aging, since sleeping problems are much more common as people get older. Whatever the reason, the sleeping problems were magnified several-fold once I realized I had cancer. Let’s face it – nights are the worst times for people who are frightened. During the daytime there are activities to concentrate on that take your mind off the scary “C” word, at least temporarily, but at night when it’s dark and everyone else is slumbering, the “scares” become scarier and the “what ifs” become nearly impossible to push out of your mind.

I told my internist when I was first diagnosed that I felt it would be much easier to face what I knew lay ahead if I could only sleep at night. He prescribed a sleeping pill that seemed to help some, but I still continued to struggle through many nights. One time shortly after starting chemotherapy, I felt good physically but wrote in my journal during my prednisone-induced gloominess, *“I am fighting the feeling of impending doom, which may be made worse by not being able to sleep well the last couple of nights. It’s so bad now that I am starting to dread the nighttime and become anxious when bedtime nears. Who knows, maybe it is just due to some of the drugs I am taking right now. The important thing to remember is I don’t have to face this alone or forever. Today I just need to be thankful to be alive and free of pain. I will try to think more about ordinary things instead of focusing on having cancer. I shall not waste this day!”*

When I eventually started seeing a counselor, she switched me to a different sleeping aid that also had anti-depressant effects. After taking it the first night I wrote in my journal, *“I think it made matters worse. I awakened over and over in the night, and in the morning I felt worried and discouraged. I think I need to stop focusing on sleep and stop taking drugs and give my body a chance to relearn its own rhythm. I need to stop stewing and fretting so much in general – it’s time to let go and let God!”*

It was at that point I came up with a second mantra I found most helpful for falling asleep or going back to sleep when I awakened during the night. I would concentrate once again on breathing slowly in and out, but this time repeatedly praying two words of the following phrase with each inhalation and exhalation, “Dear God, bless me; cleanse me, rest me.” I found when I channeled my thoughts in this way from my own inability to help myself to the reassurance of God’s presence there with me, I would start to forget whether it was time to say the “bless me” or the “rest me” part of the prayer as I drifted off to sleep. I still use that mantra today when I need to be reminded that God takes care of me even in the dark.

Many people who don’t sleep well at night simply nap during the daytime to make up for it. Several fellow cancer survivors told me they napped daily while taking chemotherapy, but napping has never been my strong suit. I was one of those kids who hated nap time in kindergarten and refused to take naps

long before my parents were ready for me to give them up. Chemotherapy didn't change that, and even when I did nap during the day, twenty minutes was my maximum sleep time. Jay, a man who truly enjoys naps and feels anything under an hour doesn't count, announced he was going to give me a "D- in napping!" Then when Erin came to stay with us for the transplant, she joined forces with Jay and the two of them tag-teased and cajoled me mercilessly.

Erin even reported this major flaw in my patient skills for the world to see in some of her livejournal entries during my transplant. Her comments led to some humorous exchanges once the scariest and "awfullest" days just after the transplant had passed. For example, when Erin finally left my bedside for some much needed R and R over Memorial Day, I took over writing my journal entries and tried to redeem myself. I entitled the first of those entries "*Proclamation from the Napping Queen.*" In it I declared, "*I want to set the record straight about napping. No longer shall there be finger-pointing and name-calling about my inability to do it. I can now go to sleep at the drop of a hat any time of the day or night. I realize this may come back to haunt me later on, but for now it is a blessing.*"

When Erin returned to the hospital the next day and read my entry, she left the following comment entitled "Truth Stretcher" on the website: "Aha! I return the journal to your capable hands and what is this I read? My mother has been spreading falsehoods, or at the very least has spoken far too quickly and optimistically. For a woman who claims to "go to sleep at the drop of a hat any time of the day or night," you surely haven't been utilizing this new-found power lately! I suggest you retract your claim to the title of Napping Queen - or far better yet - try harder to live up to it! Even if I'm no longer officially your caregiver, I feel comforted by the continuing opportunity to nag."

It pleased all of us that I was obviously starting to feel stronger and more capable of fighting back by this point, since I retorted in my next entry, "*To Erin the Nag, I do hereby retract my statement about being the napping queen. I guess I got a little carried away in the moment. I am still a long way from getting a passing grade in napping, although I did take a half-hour nap this afternoon, if that counts for anything.*"

The following week I started another of my livejournal entries with, *“I just awakened from a nap, which I thought was terribly newsworthy given how many people have proclaimed me a napping failure. I’m afraid I only slept twenty minutes, but at least that should count for something, and I have done it twice this week. Do I hear accolades? An ataboy? Could I talk you into slight nods and muted mentions of baby steps? That will do for now.”*

Declining to be Defined by Disease

Although cancer survivors have been through a harrowing ordeal that is likely to leave an indelible mark, I believe it’s important for them to be able to leave the cancer behind and move on with the rest of life once they achieve remission. Unfortunately, that isn’t always easy, and I have known some survivors who, in essence, have continued to define themselves by their cancer experiences for the rest of their lives. They seem to wear the experience of having survived cancer like a badge, perhaps so others who meet them will either feel compassion or somehow revere them for fighting the good fight against such a formidable foe.

It’s not hard to see how this can happen when a cancer diagnosis and its treatment necessitate an inordinate amount of attention on the patient that may be hard to give up afterward. For example, I remember what a shock it was to me when I left the hospital after being an inpatient for three weeks during my stem cell transplant. Suddenly I was expected to leave the ultra-protected environment of an “inpatient” in which every drop of liquid I drank or excreted was duly measured and every aspect of my existence charted for posterity. Now all of a sudden I would be merely an “outpatient.” When they told me I would only need to stop in at the treatment center for regular blood counts every few days, I wanted to snap back, “What do you mean – don’t you care how much I pee anymore?”

Of course, they still cared about me and they knew they weren’t sending me out alone. Jay and Erin had been appropriately trained and were there with me to constantly fuss over me and make sure I was eating and taking my medications on time. However, it didn’t seem right that I would no longer be seeing Dr. Vose every day. It also disturbed me somehow that the transplant nurses had suddenly shifted their

attention to their other “sicker” patients, even though I knew those patients needed their care more than I did. Thank goodness, I got past that nonsensical kind of thinking rather quickly, for I believe people who can’t get past it remain defined by their disease. As my friend Peg says, “They not only had cancer, they still have cancer – or rather cancer has them.”

Getting past successful cancer treatment means having to go back to “normal” life, whatever that is. When I finally received the wonderful news I was in remission, I vowed to myself to remain eternally happy and thankful to be alive for the rest of my days. Never again was I going to rush to keep from being late to anything or let the normal irritations of the world get me down. The day after Christmas that year I wrote, *“Any time I have less than positive thoughts about something, I will remind myself just how fortunate and thrilled I am to be alive, and then I will remember that the rest is all small stuff.”*

I kept that promise and was on cloud nine – for a while. However, as time went on, I realized all of the regular problems of life (the ones I had thought of as so trivial while fighting for my life) were starting to creep in and nag at me again. No matter how often I told myself I should be grateful for everything about life, I still had to deal with some of the long-term side effects of treatment, such as chronic diarrhea and severe nighttime leg cramps. As compelling as my happiness over being alive was, there were times when I couldn’t help but mourn the loss of my old vitality. There was also the problem of having to face the fear of recurrence.

By the following February I was knee-deep in writing grant proposals. I was also giving lectures to the medical students and conducting a graduate class I had never taught before. One day, when I felt particularly stressed, I realized my life had pretty much gone back to what it had been like before my diagnosis. I was stunned and ashamed of myself. I wrote an email to my family that said, in part, *“I feel like I’m barely managing to keep my head above water, even though I’m paddling like mad. I am trying very hard not to let myself get caught up in the old ‘time stresses’ that used to consume me. Each time I feel myself start to tense up like I used to, I stop and remember it’s not that big a deal and I don’t need to hurry to do it. Hopefully that is one of the lessons I can carry with me to the other side of all this.”*

There is no doubt my cancer experience has changed me and the way I live my life, but I still have to guard against becoming distressed over things I promised myself would no longer upset me. What helps more than anything else at those times is to stop and think, “If I found out today that my cancer is back, would this be of any consequence at all?” Most of the time, the answer to that question is a resounding, “NO!”

I never want to forget how it feels to wake up each day with fear hanging over my head, because that memory will provide me with appropriate compassion for others who are now living in fear. At the same time, however, my prayer is to be reminded daily of how wonderful ordinary life can be so the “small stuff” will never again be such a determining factor in how I see the world.

Glaring at the Gifts of God

I believe that God, the grand planner of the universe, bestows a multitude of gifts on each of us. Unfortunately, I’m afraid many of us often fail to recognize or understand those gifts, so we may reject them or even get angry over the circumstances accompanying them. One thing I have learned from my cancer experience is that many of the God-given “gifts” that I didn’t want and most certainly wouldn’t have chosen at the time turned out to be true blessings for which I will always be grateful

The first unappreciated gift that comes to mind occurred two years before my diagnosis when the Creighton University Pharmacy Department launched a web-based doctoral program. This required every faculty member teaching in the curriculum to prepare special on-line versions of each lecture for the web-based students, as well as presenting the lectures orally in the regular classroom setting. I already felt overwhelmed at that time with writing and reviewing manuscripts and grant proposals, training graduate students, and running a research lab, so I was terribly disturbed by the thought of creating new on-line versions of all the lectures I was supposed to teach the following semester. In the end, I did prepare the necessary lectures, but I grumbled and carried on throughout the process to anyone who would listen.

What I couldn’t know at the time was those on-line lectures would become the saving grace that allowed me to fulfill my teaching commitments in the pharmacy course during my illness. Having the

ability to provide the on-campus students with access to the on-line versions of my lectures meant I could teach them even when I was too ill to be physically present in the classroom. Having that kind of backup plan went a very long way toward relieving my daily stress over whether I would be able to make it to all of my lectures. It literally turned out to be a beautiful gift to me, despite all of my initial complaints.

Sometimes I also think what we perceive as “our” gifts may actually come about as a side-effect of a God-given gift to someone else. An example of this occurred when I was supposed to have the CT and PET scans for my one-year post-transplant check up. Because I had received bad news from so many previous sets of scans and knew I had a very good chance of relapsing, I spent the week before the scans feeling anxious and distressed over what they might show. I was trying the night before the scans to shore myself up for whatever the news might be when the hospital called at 9:40 p.m. to tell me the PET scan technician had been in a car accident so my scan would need to be cancelled and rescheduled at some unspecified time in the future.

I became distraught at the news because it meant I would not only have to wait longer to get the results but also have to go through the whole pre-test waiting process again once the scans had been rescheduled. As much as I tried to direct my emotions toward concern for the injured technician and tell myself that God must have a reason for delaying the test, I was most certainly NOT happy about the turn of events. I tossed and turned throughout the night, but early the next morning the hospital called again, this time to say they had found another technician to do the scans and I could still have them done that day if I could come in at 11:00 a.m. rather than at 8:00 a.m. I eagerly agreed and said a prayer of thanks to God for hearing my cry.

While I was at the hospital waiting for the scan three hours later than originally planned, I happened to overhear the woman who had been my patient liaison talking to a couple about the transplant center and what they could expect if they decided the husband would have a transplant there. Both the patient and his wife looked so distraught that I found myself overwhelmed with empathy as I remembered how scary it was for me at that point in my own transplant journey. It is unlike me to go up to strangers and strike up a conversation. However, I was so touched by their obvious angst that I felt compelled to tell

them I had been where they were just a year before and I was living proof a transplant is “doable” and that it can work. I gave them my phone number in case they had questions or just needed to talk to someone who had “been there.” Interestingly, telling them my success story redirected my focus away from my own fears, and I suddenly felt much more confident about getting my scan results. A short time later the patient liaison who had been talking to the couple came to find me. She gave me a big hug and told me the woman had broken into tears of relief right after I left, saying, “I really needed to talk to that lady!”

I didn’t hear any more about the couple after that, so I figured the man must have decided to go elsewhere for his transplant. Then exactly one year later he called to thank me and tell me the doctors had decided he wouldn’t need a transplant after all. He said he wanted to celebrate with me the fact that both of us were still alive. Together we decided we would take turns calling each other every year on that same date to remind ourselves of how fortunate we are and how good life is. We have kept that promise every year to this day.

Of all the times I needlessly got mad at one of God’s gifts, I think I was most angry when Erin came to spend a whole week with Jay and me right after I had my second chemotherapy treatment. She was in a doctoral program on the east coast at the time, but it was her fall break from classes. My blood counts were at their very lowest of the cycle right then, so I couldn’t go in to work either. We were both so excited about getting to spend that time together, and we planned our days with great relish. The day after her arrival, however, Erin developed a high fever and terrible headache. Thinking she must have an infection of some sort, we decided she needed to be quarantined to the basement level of our home. It seemed so unfair! We had meant to spend all of our time communing and enjoying each other, and instead she felt totally miserable and I felt powerless to do anything to make her better. I wrote in my journal, *“OK, this is the first time I have been truly mad at God.”*

Because we were both so worried I would come down with whatever ailment she had, Erin stayed in the basement and I stayed on the upper floor of the house for five days. When she did venture upstairs, she conscientiously wiped off anything she touched with Purell and then went right back down again. We

weren't able to spend any quality time together until she started to feel better and my blood counts came back up the day before she was scheduled to leave. I had a very hard time trying to figure out why this had to happen and ruin all our plans until blood tests confirmed later that Erin had been infected with West Nile Virus. West Nile is spread by the bite of a mosquito and is not passed from person to person, so Erin wasn't contagious and couldn't have infected me after all. West Nile Virus in the central nervous system also can kill even healthy young people like Erin, so it was fortunate she was at our house where we could have rushed her to the hospital, if necessary, instead of being so ill all alone in her apartment.

The day Erin called to tell us the results of her diagnostic blood tests showing it was West Nile, I wrote in my journal, *"I guess God once again knew way better than I did about how to handle things. It turned out to be a blessing after all, even if we didn't get to enjoy it. Thanks, God, but it sure would have been nicer if you could have figured out an easier way to bless us."* None of us gets to choose our gifts from God. Thank goodness that's true, since we would undoubtedly turn down some of the very best ones.

Looking back on these types of experiences makes me question why God doesn't let us know more at the time about why our unwanted gifts are being given and what we are supposed to do with them. Surely it would be a whole lot easier to accept them if we only knew, but I found an answer to this puzzle in a book named *God Calling* (A.J. Russell, ed.). This little book, which was written nearly eighty years ago, relates each day of the year what two unnamed women believed to be messages they received from God. The entry for March 24 reads, "I am here. Seek not to know the future. Mercifully I veil it from you. Faith is too priceless a possession to be sacrificed in order to purchase knowledge." I have become convinced, partly through my cancer experience, that God truly does plan the best for us. We just need to trust Him more and worry less. This realization has led me to devise yet another mantra I use when I start to wonder why things are happening the way they are. At those times I simply remind myself, "God does really good work if we just don't muck it up."

Basking in the Beauty of Belief

In the publication *The Word for You Today*, the devotional for July 28, 2011, includes this statement: “Between praying for a miracle and getting one, you’ll be tested, you’ll grow, and you’ll learn to trust God more than you ever thought possible.” That was most certainly true for me.

When I was a child, I saw my father as a shining example of a man who truly believed in God. I never thought to ask him when or how he came by his strong faith, but it seemed clear to me that believing made a huge difference in the quality of his life. I would look longingly at his unshakable conviction and want so badly to be able to claim it for myself.

But faith isn’t something you can borrow or catch. The best I could do at that point in my life was hedge. I would say, “I will believe there is a God, and then if I find out at the end of my life it was all a bunch of hooey, at least it will have made my life better while I was living.” That stance worked reasonably well for me until I suddenly found myself facing the very real possibility that the “end of my life” might actually be at hand. I realized then that half-hearted believing wasn’t enough, and I both wanted and needed more. I had always been an active church member, read devotionals daily, prayed at mealtimes, and strived to be as “Jesus-like” in my dealings with other people as my frail human nature allowed. But when it came to prayer, that deep kind of personal commitment to regular communion with God, I knew I was a miserable failure. At first I couldn’t even bring myself to ask God to heal me. That’s why I chose the words “cleanse me” rather than “heal me” for my bedtime mantra. Somehow I didn’t feel worthy to suddenly ask for something so huge when I had been “absent” from private prayer for so long. Instead I just prayed for courage and hope and strength and wisdom to get through whatever I had to endure with as much dignity as I could manage.

Jerome Horton is credited with saying, “We talk about finding God – as if He could get lost.” I can’t point to a specific time or instance in which I “found” God, but I started setting aside a regular prayer time each day. Gradually, as it became easier to talk to Him about whatever was on my mind, He became more and more real to me. By the end of my sixth chemotherapy cycle I finally wrote in my journal, “*This is about the first time I have felt comfortable praying that I be healed if there is any way that can fit*

into God's plan. Most of all, however, my prayer is still for my own awareness that God is there with me no matter what so I can face these last days of uncertainty, as well as whatever the test results turn out to be."

Today, in large part due to my cancer experience, I can say with certainty, "I not only *believe* there is a God, but I *know* there is a God who watches over me and takes care of me at all times, whether I deserve it or not." And if there is anything I could give to other people trying to fight their way through the maze of cancer, it would be that kind of certainty. It's important to explain, however, that I don't believe in God because I got well. I believe because every time I thought I couldn't stand any more bad news or go through one more treatment, I would ask God for help; and invariably something would happen or someone would show up and provide exactly what I needed to keep going.

A few days before I was scheduled to start chemotherapy, I awakened from a horrible dream that I had become mentally incompetent and lost my job. I felt forlorn and frightened and unsure about whether or not I could "do this." I sat on the edge of my bed and cried, and then I prayed through an entry in my journal, "*Listen God, if I am going to be able to get through this and make something out of it, you're going to have to help me because I am really a mess.*" I finally dried my tears, splashed cold water on my face, and went to work in my laboratory, which was located at the Omaha VA Medical Center.

When I arrived at the medical center, I happened to pass one of their longtime volunteers in the hallway. His face has been disfigured by years of fighting skin cancers and the innumerable surgeries required to remove them. During all my years of affiliation with the hospital, I had watched many people turn away when meeting him in the hallway, presumably because they didn't know how to respond to someone who looks like that. I knew their avoidance had to hurt him, so I had always made a point to look directly at him and smile when I passed him. He always smiled back, but we had never really spoken to one another.

On that morning, when I smiled as usual and then turned a corner to go to the research wing of the hospital, I heard him say, "Hey, do you know you're beautiful?" I turned back in amazement and he continued, "I'm saying that from my heart, and I don't usually tell people things like that." I thanked

him, told him I especially needed to hear something like that right then, and went on my way. The next day I saw him in the hallway again and asked him how it felt to be an angel sent from God. I thought he should know I felt God had sent me a message through him. He said it felt good, and after that day we became friends who bolstered one another through some very difficult days.

Another time when I was at the UNMC treatment center for a simple blood draw that should only have taken five minutes, Persnickety Port acted up and I had to stay there for over two hours while the nurses unclogged it. I was in a two-person treatment room the whole time with a woman from Ohio who was there to have a stem cell transplant. She had already been given her high-dose chemotherapy and was feeling quite miserable, but for some reason she seemed to enjoy talking to me between bouts of nausea.

Dr. Vose had already told me I might have to have a transplant myself, and it terrified me to be in that room for two hours listening to the doctors and nurses and pharmacists who came in a procession to explain to the woman what to expect the next day after she received her stem cells. They kept giving her what seemed like an endless stream of drugs in preparation and, of course, had to describe the possible unpleasant and scary side effects of each one. By the time I got out of that room I was incredibly anxious and had somehow convinced myself that God must have put me there in order to prepare me for what was to come for me as well.

On the way back to my work office, I was literally shaking. All I could think of was, "I have to call Peg. I have to talk to her. I need her to help me calm down." When I got to my office and picked up the phone to call her, I found a message from Peg telling me I had been on her mind all morning and she wanted to let me know she was at her sister's house. She left her sister's phone number in case I wanted to get hold of her, even though she had no idea what had happened to me that morning or that I desperately needed to talk to her. I immediately called the number, and when I told Peg how frightened I was because I was sure it meant I would have to have a transplant. In her infinite wisdom, Peg simply said, "Did it ever occur to you that maybe God put you there so you could help the other woman instead, and that if you end up having to go down that road God will surely send someone to help you too?"

Relief flooded over me, and I wrote in my journal that night, *“How could I not believe in God when things like this keep happening?”*

I would love to say I have continued without interruption to have the same kind of intense daily conversations I had with God during my illness, but that would be a lie. Perhaps it’s because I no longer feel so desperate and now have many more details of ordinary life crowding into my time, but whenever I allow those “other things” to take precedence in my life, I start to miss the closeness I felt to God when I was sick. When I don’t take the time for concentrated prayer every day, I start to feel awkward once again and unsure of what to say to Him. I guess it’s like all other relationships – you have to put forth the effort to keep it going in order to feel comfortable in it. Obviously, I never want to go back to that time of extreme illness, but I have learned from it just how important daily prayer is to my life. I also have learned that God does not change. He is always there, ready to listen and provide guidance and help me when I need it. His arms are always there for me to crawl into. His hand is still ready to hold mine. I am the one who sometimes forgets to stop all those unimportant-in-the-grand-scheme-of-life activities and draw near to Him – and that can always be fixed. What more could any of us ask for?

What Cancer Has Given Me

by Martha Nielsen

I was asked several years ago to give the Survivor's talk at the Omaha Cancer Survivor's Day festivities. I began by saying that people seem surprised when I tell them that if I had the chance to go back and erase my cancer experience, I wouldn't do it. I then went on to give them my following top ten reasons, à la David Letterman:

- #10 I have had four major surgeries since my transplant. Any time I got worried about the outcomes or the expected long recovery times, I was able to just say to myself, "Hey, at least it's not a terminal illness!"
- #9 Like most women, I wasted years of my life wishing my hair was thicker and curlier and most certainly a more interesting color. Now, after going without hair for fourteen months, I am much happier with what I've got.
- #8 Like many people, I also spent a lot of time worrying about my weight and wishing I didn't enjoy food so much. Having to literally force myself to eat for a couple of months after my transplant has made me realize that enjoying food is a wonderful gift, and without it life is far less pleasurable.
- #7 Cancer taught me that getting old, with all of its changes and aches and infirmities, looks a whole lot better if you think you're not going to get to do it.
- #6 I have learned there are many, many ways to provide support and comfort to another person and not all of them require words. Now when I don't know what to say when someone is in crisis, I understand that just being there is enough.
- #5 Cancer pointed out to me that the vast majority of the activities I frantically try to fit into every day are really not very important after all.
- #4 One of the hardest lessons cancer taught me was how to be a gracious receiver. For me, the secret to that was realizing that refusing to be a receiver deprives another person of the joy that giving brings.

#3 Through my cancer experience, I learned the best way to cope with fear or distress or anger or loneliness is to look around and find someone else to help.

#2 Because I had cancer, I am not nearly as afraid of dying as I used to be. When I went into congestive heart failure and my temperature shot up to 104° post-transplant, it was terribly hard on the people who loved me, but I simply don't remember the next three days. Although I have no desire to die any time soon, the thought is far less scary to me now.

#1 The most important thing cancer has given me is the certain knowledge that there is a God. I can say that not because I got well, but because every time I asked God for help, He sent exactly what I needed to keep going. If there is anything I wish I could pass on to others with cancer, it would be that blessing of certainty.

I believe with all of my heart that my battle with cancer was God's way of teaching me lessons such as these so I can share them with others. I will always be grateful for each of them, but I truly hope the next time He has a lesson for me, He will just send me an e-mail.

Literature Cited

Burkett, Larry. *Nothing to Fear*. Chicago: Moody Publishers, 2003. Print.

Burpo, Todd. *Heaven is for Real*. Tennessee: Thomas Nelson, 2010. Print.

Gentry, Erin. "My Gift to Mom for Her Second Birthday: An Adult Daughter's Perspective." *Caregivers' Guide for Bone Marrow/Stem Cell Transplant*. Eds. Myra Jacobs and Jean Jones. National Bone Marrow Transplant LINK, 2007
www.nbmtlink.org/resources_support/cg/cg_mom.

Gerard, Vickie. *There's No Place like Hope*. Washington: Compendium, Inc, 2001. Print.

Remen, Rachel Naomi. *Kitchen Table Wisdom*. New York: Berkley Publishing Group, 1996. Print.

Roper, David. *Our Daily Bread*. RBC Ministries, Grand Rapids, MI. © 2002. Reprinted with permission. All rights reserved.

Russell, A.J. *God Calling*. New York: Jove Books, 1978. Print.